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PARENTS' EXPERIENCE OF HAVING A VERY LOW BIRTHWEIGHT PREMATURE INFANT

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BY

BRENDA A. MANASSE

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF MASTER OF EDUCATION
IN
COUNSELLING PSYCHOLOGY

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA
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THE UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled "Parents' Experience of Having a Very Low Birthweight Premature Infant" submitted by Brenda A. Manasse in partial fulfillment of the requirements for the degree of Master of Education in Counselling Psychology.

W H O Schmidt
Supervisor

Mary Ann Bibby

Peggy Anne Field

Date February 13, 1987

DEDICATION

This study is dedicated to the five mothers and five fathers and their five infants whose stories are told in it. Parents' hospitality and their willingness to talk freely about painful matters, enabled our meetings to become for me not only "research" but enriching human encounters. Through them, I became aware of the courage and resilience of ordinary people quietly facing and often surmounting tremendous difficulties.

ABSTRACT

The purpose of this study was to uncover the meanings for parents of the events they experienced in the course of having a very low birthweight premature infant. A phenomenological approach was used to explore in depth parents' experiences from the time of conception until infants had been home for several months and in two cases, for 16 months. Five Caucasian married couples, the majority working class, were each interviewed on three occasions, a semi-structured interview process being employed.

Close study of the complex material revealed five themes which are presented with illustrative quotations from parents' narratives. The themes were couples' physical and emotional traumas during pregnancy and the perinatal period; couples' experiences in the neonatal intensive care unit; problems after infants' arrival home; parents' experiences with professionals, and finally, the availability of support systems and their differential effects on parents' responses in various situations.

Parents' individual preexisting personalities and belief systems were two major factors influencing the manner in which each parent reacted to events. Difficulty obtaining information about premature infants and problems with access to and rapport with professionals, proved prime exacerbating factors. Other stressors included the distressed behaviours of grandparents and siblings, as well as fathers' reluctance to discuss affective matters with their wives and to participate substantively in housework and child care.

The concept of crisis not as an event but as behaviours of varying severity in response to an event, was discussed. The concept of parents' performance of four essential psychological tasks as a precondition for attachment to their infants, was found to have moderate applicability to the parents in this study. The possible societal and personal origins of fathers' minimal disclosure during interviews, of their emotional reactions to events, were discussed, and future research methods to take account of this problem, were suggested.

Practical implications of the study's findings, as well as parents' own recommendations for enhanced supportive efforts by professionals, were included. Finally, a plea was made for increased moral and financial commitment to assisting parents of very low birthweight premature infants.

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DEFINITION OF TERMS

The terms "premature" and "preterm" are both used in the psychological literature. Honouring the usage of "premature" by the parents interviewed for this study, the researcher has chosen it as her preferred term.

Age adjusted for Prematurity -	premature infants' age calculated to take account of their immaturity due to incomplete gestation.
Infant -	A baby from birth until the emergence of coherent speech - 2-3 years of age.
Neonate -	an infant aged 1-28 days.
Primigravida -	a woman pregnant for the first time.
Multiparous Parents -	parents who have had more than one pregnancy resulting in live offspring.
Perinatal Period -	the period from the 28th week of gestation to the 28th day after delivery of the infant.
Postnatal Period -	the first 6 weeks after the birth of the infant.
Prepartal Period -	the period of time preceding childbirth.
Intrapartal Period -	the period of time during which a mother is giving birth to an infant.
Postpartal Period -	the period of time immediately following the mother's delivery of an infant.

CHAPTER I

Overview

Introduction

For most couples, parenthood is an experience of mixed emotions, with anxiety and doubt intermingled with joy and a sense of achievement. For parents of fullterm babies, the positive aspects are more likely to outweigh the negative ones. However, the reverse situation applies for most parents of premature babies during the first months or even years after their babies' births.

Despite the great improvement over the past 20 years in facilities for helping premature infants and their parents, the experience of having a premature baby is still a traumatic one for most parents. This is particularly true of those parents who deliver very low birthweight (VLBW) premature infants, that is, infants who weighed 1,500 grams (3.3 lb) or less at birth. The mothers of these infants will often have endured pregnancy and delivery complications and both parents will have been shaken by the unexpected turn of events leading to premature delivery. They are likely to have been dismayed by their infants' initial physical unattractiveness, their frighteningly fragile appearance, their susceptibility to perinatal health complications and their consequent extended stay in hospital. In some cases, the sequelae of extremely premature birth will make later care a particularly arduous task for the parents. Many parents will have other children to care for and they may also be subject to life stresses such as financial problems, unemployment, inadequate support systems and individual personal problems. These additional difficulties may well hamper these parents' efforts to effectively handle the problems associated with giving birth to and rearing their very special babies.

Purpose and Rationale for the Study

The purpose of this study was to explore parents' experience of having VLBW premature babies. The study was prompted by several concerns. Firstly, only a modest number of studies have explored this area of parental experience. There is a need for further research because, while the number of these infants born annually is very small in comparison with the total number of live births, the impact of these infants is felt in the lives of thousands of parents. Moreover, improved technology has resulted in an increase in the number of surviving VLBW premature newborns over the past 15-20 years (Stewart, Reynolds and Lipscomb, 1981). This means that increasing numbers of couples are facing the many stresses attendant on parenting these frail tiny babies.

To date, none of the existing studies of these parents has presented a continuum of their experience, beginning at conception and following them till their babies have been home for a period long enough to enable them to gain confidence in caring for, and growing to know their babies. As a result, a total picture of the crucial events in parents' experience is missing from the literature. In addition, a description of the unique responses of mothers and fathers to events over time which would reveal each parent's individual history, personality, perceptions and values has not been identified.

This study set out to present such a picture. In so doing, it was hoped to provide information in areas that had been the object of little or no previous research. One of these areas related to the impact on fathers of becoming the parents of VLBW premature babies. The paucity of information on these fathers is regrettable for several reasons. Firstly, it perpetuates the notion of fathers as lesser partners in parenthood. Secondly, it has left us currently with little knowledge concerning which emotional and cognitive states may be experienced by fathers only. Jeffcoate, Humphrey and Lloyd (1979) have apparently conducted the only study to date that substantively focuses on comparing spouses' reactions. A third area of deficit in the research on fathers of VLBW premature babies, relates to the kinds of support these fathers most need. The available data from existing studies omits mention of fathers' specific needs, concentrating on parents' needs as couples.

Certainly a prime need of parents struggling with the stresses of having a VLBW premature infant, is the support of intimate family members. Yet the information on the reactions to the arrival of these special babies from grandparents and the babies' siblings is extremely scanty. This is unfortunate since the support, or lack of it, on the part of close family members can either ease or complicate parents' efforts to deal with the complex of situations they encounter each day.

Parents' opinions and related recommendations regarding the spectrum of professional and informal support they received, have rarely been elicited by researchers, Lissenden (1984) being one exception. This researcher believed that parents might be best able to formulate ideas on this topic when the worst of the stresses relating to their babies' survival and stabilization at home were over, and they had had time to ponder their experiences. The present study was therefore planned with this possibility in mind and so commenced when the babies had been home for at least one month.

Methodological considerations provided a further reason for undertaking this study. The studies to date have used the prevalent empiricist approach and have yielded valuable information. However, there has been some acknowledgement that the research methods used were unable to reveal the uniqueness of individual parents' and individual couples' perceptions and responses (Benfield, Leib and Reuter, 1976). Since the phenomenological research approach emphasizes the study of the subjective experience of individuals, that approach was selected as the method for this study. A further reason for choosing the phenomenological approach was to ascertain to what extent the information obtained through its particular methods would confirm, disconfirm or elaborate on that so far presented by empirical researchers.

Finally, it was the researcher's hope that information and recommendations from parents would assist concerned professionals both within and outside the hospital setting, in refining and adding to existing efforts to support parents who have had VLBW premature babies. Not only would this improved support assist parents in weathering the vicissitudes attending their babies' births and negotiation of the months after their homecoming, but it might well have a beneficial effect on parent/child relationships. There are research findings which indicate that mothers of VLBW premature babies who request and utilize support services, both formal and informal, are more likely to develop mutually gratifying relationship with their babies in infancy (Crnic, Greenberg, Ragozin, Robinson and Basham, 1983) and beyond (Philipp, 1984) than are mothers who do not obtain such services. Unfortunately, no studies have been done to establish whether the same situation applies to fathers of VLBW premature babies.

Prematurity

Definition

Agreement on the criteria for defining prematurity has been slow in developing. Birthweight has most often been used as the criterion of prematurity in epidemiological studies (Keller, 1981) as well as in medical and psychological literature, because it can be reported more accurately than gestational age. However, in the late 1960's, the

American Academy of Pediatrics (1967) decided that the prevailing international definition of premature infants as those neonates with birthweights of 2,500 grams (5.5 lb) or less, was inadequate. They were concerned that this criterion obscured the fact that the birthweight of some of these premature babies could reflect not only gestational age but also aberrant intrauterine development. Their concern arose from the fact that there are a number of etiological factors and related sequelae that are unique to infants who have developed abnormally in utero and which require their own distinctive medical treatment (Vaucher, 1980).

The Academy therefore accepted a classification of newborn infants based on the relationship of birthweight to calculated gestational age which had been developed by Battaglio and Lubchenco (1967). The classification consists of three categories of neonates: small for gestational age, appropriate for gestational age and large for gestational age. Thus babies can be classified as being of normal or abnormal intrauterine development according to percentile rankings based on birthweights and corresponding gestational ages.

Members of the World Health Organization had also expressed concern about birthweight as the sole criterion for prematurity in the late 1960's and for the same reasons as those motivating the American Academy of Pediatrics. The solution of the world body was different, however. In 1969, it suggested that a gestational period of less than

37 weeks be used to identify prematurity (Hobel, 1980). The definitions of both bodies suffer from the problem of establishing the medically accurate date of conception due to irregularities in the reproductive cycles of numbers of women.

Researchers are increasingly describing the babies they study in terms of both birthweight and length of gestation and to some extent they are also including the categories of intrauterine development, presumably based on their opinion of its necessity for inclusion as a variable in their research. Birthweight, length of gestation and level of intrauterine development have all been used to describe the five babies in the present study.

Etiology

Premature labour can be related to a large number of predisposing and precipitating conditions arising from mothers' physical and psychosocial status, the status of the fetus and from external factors. Hobel (1980) believes that premature labour is often the result of the interaction of numerous factors but exact etiology is frequently difficult to determine in any one individual case.

Maternal related factors include age, maternal history, socioeconomic status, physical health, anatomical aberrations, lifestyle and possibly the psychological state of mothers. It has been suggested that mothers of 15 years and under are more prone to give birth prematurely because their reproductive systems are no yet mature enough for pregnancy (Goldberg and DiVitto, 1983). These authors also propose that mothers who bear children at a young age and at close intervals, are more likely to experience premature labour because their bodies have too little time to recover between pregnancies. The authors further point out that it is often forgotten that pregnancy makes great physical demands on mothers and some of them who may previously have been healthy, may develop problems because of the added stress of pregnancy.

Like most other researchers (Caplan, Mason and Kaplan, 1965; Hobel, 1980; Sameroff, 1981), Goldberg and DiVitto (1983) see prematurity occurring most frequently among mothers of lower socioeconomic status. Hobel (1980) views these mothers as handicapped by such factors as poor nutrition and inadequate prenatal care, as well as unhealthy personal habits such as excessive smoking, but he sees no research clues yet as to how these and other possible variables interact to induce premature labour.

Hobel (1980) notes that many studies have shown a relationship between situations that cause stress and premature labour. This opens up the interesting possibility that the physiological and biochemical changes that occur in the body during prolonged stress, may be a factor in producing the low maternal serum progesterone levels that Hobel and associates (1980) have found to be one of the two most accurate predictors of premature delivery, the other being a previous premature delivery. Goldberg and DiVitto (1983) state that obstetricians and psychiatrists have speculated for a number of years that psychological stress may play a part in precipitating premature labour but that research has not yet established a definite relationship.

Several maternal physical conditions are associated with premature delivery. Economically poor mothers are more prone to develop illnesses that complicate pregnancy, such as diabetes, kidney and heart disease (Goldberg and DiVitto, 1983). Other physical conditions occur in mothers of all social backgrounds. One predisposing condition is toxemia, the condition of high blood pressure suffered by some mothers during pregnancy. Congenital anomalies of the uterus have also been found to precipitate premature labour. Werthmann (1981) describes several reproductive problems that can precipitate premature delivery. Premature spontaneous rupture of membranes followed by spontaneous labour, occurs in 15-20% of premature pregnancies. This condition is associated with cervical incompetence, that is, the inability of the cervix to remain closed during pregnancy because of poor muscle tone. The weight of the fluid-filled sac containing the fetus, proves too much for the cervical muscles, causing the sac's membrane to tear (Ellwood and Anderson, 1981). Various placental anomalies are associated with premature deliveries, either spontaneous or planned. Some anomalies can give rise to life-threatening hemorrhaging associated with partial or total rupture of the placenta from the uterus. Other placental problems may result in inadequate nutrition for fetuses. Placental malfunctions often necessitate the induction of premature labour out of concern for the wellbeing of the fetuses.

Finally, Werthmann (1981) notes that some premature deliveries arise from iatrogenic factors, that is, factors related to medical practice. One example he cites is the spontaneous onset of premature labour after surgical procedures such as amniocentesis. A second example would be error in correctly assessing the length of gestation for the purpose of either inducing labour or performing a repeat caesarean section prior to the onset of labour. Werthmann states that such error is reportedly responsible for 10-15% of premature deliveries.

Even taking into account the numerous factors associated with premature delivery, approximately 50% of all premature births still appear to be unexpected and inexplicable (Goldberg and DiVitto, 1983).

Incidence

In 1982 in Canada, 3.3% of babies weighed 2,500 grams (5.5 lb) or less at birth and did not complete the 37th week of gestation (Statistics Canada, 1984). Within this population, 0.9% were VLBW babies, that is premature babies who weighed 1,500 grams (3.3 lb) or less at birth.

Reports on the incidence of prematurity in the United States suffer from inadequacies and inconsistencies in definition of prematurity as well as discrepancies in estimates of percentages of premature live births (Hobel, 1980; Keller, 1981; Selby, Calhoun, Vogel and King, 1980;

Werthmann, 1981). The only statistics that come close to being truly comparable to the figures for Canada, are those supplied by Keller (1981) for the period 1967-73 and these are confined to white babies. He states that during this five-year period, the percentage of white babies born in the United States before completing the 37th week of gestation and weighing below 2,500 grams at birth, was 2.8%. He further states that this figure is generally true for European populations as well. The higher Canadian figure of 3.3% may perhaps be accounted for by the fact that it includes all races, possibly indicating that the rates of premature delivery among non-white mothers is higher, as is known to be the case in the United States (Keller, 1981; Werthmann, 1981).

Survival Rates

Comparative statistics have been presented in a number of studies. These point out the dramatic improvement in outcome for VLBW premature babies since the late 1960's. For instance, Goldberg and DiVitto (1983) report that in the early 1960's, most premature infants weighing less than 1,000 grams (2.2 lb) failed to survive, whereas in 1974, the Hospital for Sick Children in Toronto reported a survival rate of 51% for these tiny babies.

In a review of data from parts of Canada, the United States, Australia, Great Britain and Europe, Stewart et al. (1981) state that the proportion of healthy surviving VLBW premature infants has trebled since 1960 with the proportion of handicapped infants remaining at 6-8%. They define these latter infants as suffering from abnormalities likely to prevent them from leading normal lives.

The authors attribute the improved outlook for VLBW premature infants to advances in knowledge and in obstetric and neonatal care, since there does not appear to have been any change in the parents' socioeconomic status or other characteristics of these infants that could account for the greatly improved prospects for their survival.

The Evolution of Improved Care for Premature Infants

Until the French obstetrician Pierre Budin invented the incubator in the early 1900's, few premature babies survived delivery. Budin wrote the first textbook on neonatology. It was published in 1907 and in it he emphasized the importance of continuing mother-infant contact starting at birth. However, his American student, Martin Couney, did not teach or practice this principle on his return to the United States where he concentrated on exhibiting premature infants in incubators for profit (Kennell and Klaus, 1982).

In North America, little progress was made in treating premature babies until premature baby units were established and neonatology subsequently became established as a specialization in the early 1960's (Goldberg and DiVitto, 1983). At this point, research into the etiology, treatment and sequelae of prematurity began to accelerate. Regional Neonatal Intensive Care Units (NICU's), mainly based in university settings, developed in the 1970's and were designated as Level III centres or tertiary centres. People living outside the cities where these centres are located, have their premature newborns transported from their local hospitals to the centres (Balderston, 1983).

North American NICU's remained closed to parents until a number of studies performed in the 1950's and 1960's proved that parental visiting did not increase rates of infection (Kennell and Klaus, 1982). However, perhaps the most important factor in persuading hospitals to allow parents greater access to their infants, has been the work of the paediatricians Marshall Klaus and John Kennell. In their book Maternal-infant Bonding (1976) they stressed the importance of mother-infant bonding, that is, their close contact from the moment of delivery. They also conducted research to investigate ways to help parents feel comfortable in the NICU setting and to become increasingly involved in the care of their infants. Although some of the underlying assumptions related to the concept of bonding have recently been questioned (Elliott, 1983; Sluckin and Sluckin, 1982), most tertiary centres have adopted some of the practices recommended by Klaus and Kennell. Now, not only mothers, but fathers, siblings and relatives and friends have extensive visiting rights.

Summary

The births of fullterm babies impact most strongly on the lives of their mothers but they also affect the lives of their fathers and siblings, as well as those of their extended families. This is true as well in the case of VLBW premature babies, except that their extreme immaturity provides their parents and other family members with many worrying times. How their parents cope and the many factors that affect their coping efforts, have received only limited research attention to date.

Most of this research has focussed on mothers, yet research over the past 10-15 years has shown the importance to many men of being fathers and of growing close to their babies (Kliman and Rosenfeld, 1980; Parke, 1981). It is important that this knowledge concerning fathers of fullterm babies, be supplemented with information about the experiences of fathers of VLBW premature babies.

As Canadian parents, many of these fathers and their spouses are having fewer children than ever before (Geiger, 1986) but more of these children are surviving VLBW premature babies. These babies thus become particularly precious. It is our responsibility as a society to hear what their parents have experienced so that we can improve our efforts to help them weather the many problems they initially encounter. To the extent that they successfully deal with these problems they will be free to develop close, loving relationships with their babies. This will be ample return for the large sums of public money being expended to build, maintain and staff the NICU's and other facilities needed to assist these special families.

CHAPTER II

Survey of the Literature

Introduction

In this chapter, the development of crisis theory in general is outlined, and studies to examine its applicability to premature parenthood, are discussed. Empirical studies relating to the many aspects of parents' experience from pregnancy until two years after the birth of their VLBW premature infants, are reviewed. The relevance of several concepts in crisis theory to the situation of parents of VLBW premature infants, is discussed and two neglected aspects of these parents' experience are highlighted.

A large number of the studies dealing with parents' experience of having VLBW premature babies, describe it as a crisis (Bidder, Crowe & Gray, 1974; Blake, Stewart & Turcan, 1975; Boyle, Giffen & Fitzhardinge, 1977; Klaus & Kennell, 1982; Lissenden, 1984). However, none of the authors present their rationale for using this designation within a crisis theory framework.

This omission is particularly puzzling since Caplan (1964), still acknowledged as the most influential crisis theorist (Cohen and Nelson, 1983), based his theory not only on the research of others, but on the study by himself and his colleagues of mothers' responses to the births of their premature babies.

Crisis Theory

In his general theory of crisis, Caplan (1964) sees most of us engaged in daily problem-solving strategies which are habitual and which enable us to maintain a sense of consistency and stability in our worlds. He terms this homeostasis. What can shatter this experience of security and affect our long-term equilibrium, are periods of disequilibrium caused by stressful events whose solution is not amenable to our usual problem solving patterns. Caplan designates these periods of upheaval as crises and defines them as:

> time limited periods of disequilibrium or behavioural and subjective upsets which are precipitated by an inescapable demand or burden to which the person is temporarily unable to respond adequately. During this period of tension, the person grapples with the problem and develops novel resources, both by calling upon internal reserves and making use of the help of others. Those resources are then used to handle the precipitating factor and the person achieves once more a steady state (Caplan, Mason and Kaplan, 1965, pp.150-151).

So a crisis is not an event but a state of being precipitated by an event.

Caplan (1964) sees a hazardous event as having varying impacts on people. Some people may well find a particular event so stressful that they will respond with crisis behaviour. Others may not consider the event as problematic, perhaps because they have met similar situations before and have successful coping strategies available to them, or the event does not threaten satisfaction of a particular need or deprive these people of a needed object.

According to Caplan (1964), a crisis is experienced in four phases, each marked by a build-up in tension which he sees not as a biopsychological phenomenon but as an "organismic" one involving input and output of stimuli. In the first phase, tension is produced by the precipitating event which then evokes customary problem-solving responses. In the second phase, the comparative failure of these responses causes a rise in tension and gives rise to feelings of helplessness and incompetence as well as negative emotions such as fear, anxiety, guilt and shame. These feelings may be accompanied by inappropriate efforts to discharge tension and with persistent trial-and-error attempts to solve the presenting problem. There may be some disorganization of functioning; this depends on the intensity and duration of the tension. In the third phase, there is mobilization of both internal and external resources to deal with the problem. Previously neglected aspects of the problem may be brought into awareness, hitherto undiscovered emergency problem-solving abilities may emerge and novel methods of dealing with the situation may come to mind. The problem may be solved with the help of many people.

Needs may be met or it may be realized that certain goals cannot realistically be obtained. Relationships are reestablished with significant others and with those in wider social groupings after being strained during the peak crisis period. It may be necessary to accept a changed role in social groups as a result of the precipitating event and subsequent crisis; indeed, others in these groups may also have to accept changed roles.

The fourth phase of a crisis only occurs for those people who cannot solve the precipitating problem or avoid doing so. Tension mounts and the person feels so burdened that she or he experiences great difficulty in maintaining day-to-day living and this may finally result in major disorganization in behaviour.

Caplan (1964) believes that each of the four phases is influenced by the previous experience of the person and by that person's choices during the crisis period. Outcomes may also be influenced by the physical state of the person, chance aspects of the evolution of the stressful event, the availability of social resources and the communication systems available. In other words, crisis outcome is influenced by an interplay of external and internal factors. This conclusion is at variance with his earlier static concept of experiencing the crisis in terms of "stimulus input and outflow", but reflects his general orientation of active preventive efforts to promote community mental health by calling on the resources of the community.

This orientation is expressed in his belief that whether people emerge stronger or weaker from a crisis will depend largely on the kind of assistance they received during the critical time. He sees the most valuable form of assistance as encouragement from intimate others to talk about the distress being experienced. The values, traditions and practices of the community and the nation are also factors Caplan sees influencing peoples' efforts to negotiate crises.

Finally, Caplan (1964) sees crisis behaviour as normal behaviour. He believes it can be either growth producing or maladaptive; if the latter, there can be long-term negative consequences for the mental health of the person involved.

Since Caplan's presentation of his crisis theory 20 years ago, progress in testing, critiquing and building on it has been slow. Cohen, Claiborn and Spector (1983) comment that during the 9 years since the first edition of their book appeared (1973), little new theory has been added to the existing "limited theoretical contributions" (p.9) of pioneer thinkers like Caplan.

There are, however, some contributions worth noting. Taplin (1971) criticizes the homeostatic orientation of Caplan's theory on the grounds that that orientation precludes expression of the full range of human behaviour such as development, change and actualization. In related fashion, this limitation necessarily omits consideration of the many components of human personality that find their expression in human behaviour. Taplin's criticism is too harsh since Caplan's theory is clearly a combination of homeostatic and psychodynamic theory with an emphasis as well on the importance of ecological factors in influencing human behaviour. As mentioned earlier, Caplan believes peoples' choices have an effect on crisis outcomes and that these choices, together with assistance from others, can combine to make a crisis a growth enhancing experience.

Taplin (1971) is on more solid ground when he states that crisis theory set within the homeostatic framework precludes discussion of such major psychological areas as, on the one hand, learning, perception and communication, and on the other hand, emphasizes drive reduction and maintenance of equilibrium. Caplan (1966) stresses the latter and underplays the former.

To remedy the inadequacies he currently sees in crisis theory, Taplin (1971) presents a number of propositions relating to cognitive aspects of human functioning that he believes would help to explain more fully the complexities of peoples' behaviour during crises. Firstly, he proposes that a breakdown in thinking commonly seen during crises, arises from a physical or psychological "overload", the latter referring to an inability to handle information at variance with the person's current cognitive organization. Secondly, he sees an information processing and storage model as helpful in explaining the role of expectancies in influencing how people live through crisis situations. Expectancies are "subgroups of information about the future, incorporating accumulated information (affective and non-affective)" obtained from a variety of sources over time. Taplin views passages through crises as involving the interaction between persons with particular expectancies and the unique complex of factors that make up their specific stress situations. This proposition explains for him the fact that some people experience a crisis around a specific event whereas others do not. He believes that individuals will react to a stressful event according to whether or not their expectancies have been confirmed or disconfirmed. If their expectancies have not been confirmed, they will develop crisis behaviour.

Taplin (1971) sees cognitive concepts as helping researchers to reveal the totality of peoples' crisis experiences through studying variables like situation, type of event, personality characteristics and expectancies. He sees his approach as helping to empirically identify what combinations of variables in interaction are associated with crisis states, and with what frequency. This in turn can facilitate identifying at risk populations. He also believes his research paradigm would be useful in evaluating crisis intervention programs by comparing treated groups with matched untreated groups.

Finally, Taplin (1971) believes that the use of cognitive dimensions will assist in differentiating crises from stressful events and so eliminate the prevailing situation where a number of known types of psychological events are being labelled as crises for lack of suitable definitions of the phenomena. He proposes that the research criteria he has suggested would distinguish between crises on the one hand, and critical points, choice points and developmental milestones on the other, unless these situations had produced crisis behaviours. Presumably critical points and choice points refer to moments in peoples' lives when decisions of gradations of importance become necessary. It is Taplin's belief that his focus on studying discernible behaviour change as it occurs in specific behaviour settings will help to end disagreements where for instance, one position states that puberty is not necessarily a crisis and another position holds that it is definitely a crisis for females. He sees his approach of studying cognitive as well as affective and environmental variables, as enabling researchers to take account of all the factors, both outside and within the person, that determine the nature of that person's response to a stressful event.

There are several points on which Taplin (1971) is in agreement with Caplan. Like Caplan (1964), he is of the opinion that crises have a definite course in time and he sees the qualities of emotional turmoil experienced in crises as basically those depicted in Caplan's four phases of tension. Taplin is also in accord with Caplan (1964) that people in crisis are most amenable to requesting and receiving help during its course. The third point on which the two authors agree, is that help from informal support networks may be both necessary and sufficient during crises. As a result, they believe help from professionals may not always be essential.

Two statements by Caplan have received particular attention from other theorists. The first concept states that crises last several weeks (1964) and the second asserts that people are uniquely open to requesting and utilizing help during the crisis period (1964).

With regard to the duration of crises, Lewis, Gottesman and Gutstein (1979) compared the course of psychological upheaval in 35 people having exploratory surgery for cancer (the crisis group) with that experienced by a matched group of people having relatively minor surgery for other conditions. Five tests were administered to individual patients firstly on the eve of their surgery, then at 2, 5 and 8 weeks after surgery. The fifth test was given to all patients on the same day about 12 weeks after the close of the experiment. The authors found that only the potential cancer sufferers exhibited significant psychological changes but that their crisis states lasted anywhere from 8-28 weeks. This was certainly longer than Caplan's "few weeks".

In the view of Shneidman (1973), crises in general are of relatively brief duration and intervention need not exceed about 3 months. The only exception he makes to this statement concerns those surviving the death of a loved person. He believes that these people experience about a year of crisis. On the other hand, Auerbach (1983) rejects the concept of time-limitedness in general, firstly because few have tested the concept's validity and secondly, because he considers it untenable, given the wide variety of events and people involved in a great diversity of crisis situations.

With regard to Caplan's proposition that people in crisis are particularly open to change, Halpern (1973) found in his study of the emotions experienced by people in four different types of crisis situation, that those who had the highest crisis scores had the lowest defensiveness scores. This finding thus supports Caplan's view. Auerbach (1983) disagrees that people in crises are in a state of openness to receive help and so should receive it as soon as possible. He believes there has been no meaningful research in this area and he doubts whether crisis states in different contexts have uniform effects on people. It is his view that the optimal point for intervention will depend on the crisis event and on the particular person involved in it.

The study by Lewis et al. (1979) cited earlier, touches on several of these points. After administering several tests to a group of people having surgery to detect possible cancer, and to a matched group having surgery for less serious reasons, the researchers found significant psychological changes only in the potential cancer sufferers (the crisis group). Members experienced feelings of anxiety and helplessness initially, to be succeeded by feelings of depression and lowered self-esteem. The authors speculate that their results may represent the effects of an event of a given magnitude as a crisis inducing event, rather than the effect of cancer specifically. The authors also propose that knowledge of the order in which psychological states occur in people in crisis is necessary for maximally effective intervention programs. Auerbach would probably agree with both these statements but would point out that the test results reflect group tendencies and that within-group analyses would reveal some individual differences in psychological reactions to the feared surgery. As a result, intervention programs would have to include provision for dealing with individuals' distinctive crisis behaviours.

Like the authors in the study just described, Halpern (1973) was interested in ascertaining what specific feelings people experienced during crises. However, he wished to look more widely and sought as well information about sufferers' physical states and day-to-day functioning. A questionnaire was administered to people in four different crisis-type situations as well as to members of four groups in non-crisis situations. The four crisis-type situations were as follows: couples in serious marital conflict newly referred to a conciliation service; students who had requested assistance at a student mental health centre; newly admitted patients at a mental health institution and finally, people who had experienced a bereavement during the previous 2 weeks. Halpern found that those in crisis-type situations showed significantly more of the feelings and behaviours traditionally attributed to people experiencing crises, than did those in the non-crisis groups. Secondly, he found no significant differences in symptomatic feelings and behaviour among the various types of crisis sufferers. It is Halpern's hope that the commonality of his findings across four disparate groups will assist in helping crisis theory by presenting common affective and behavioural crisis responses as an aid to developing a definition of crisis.

The problems in attempting to define crises have been compounded by various theorists' efforts to develop typologies of crises. Caplan (1964) groups crises in terms of Erikson's two types (1959). The first type is the developmental or maturational crisis in which cognitive and emotional upset may be precipitated in some as they encounter such personal landmarks as adolescence, marriage and first parenthood. Erikson's second type of crisis is the accidental crisis which may be precipitated by the many life hazards which can pose a challenge or threat or inflict a loss of some type. Aguilera and Messick (1974, p.66) refer to these crises as situational crises and define them as "stressful events that threaten (our) sense of biological, psychological or social integrity."

Korner (1973) distinguishes between mild and severe crises. Mild crises are personal crises we all experience and which we cope with alone. This definition is in opposition to theorists' general agreement that a major hallmark of a crisis is a person's inability to cope alone and consequent need to call on outside resources. Korner's definition of severe crises as situations in which we face baffling conditions we are unequipped to handle, accords with the accepted general definition of crises.

Bloom (1963) is in general agreement with Korner's latter dichotomy (1973) when he states that crises vary in severity "with mild crises shading into the ups and downs of problem solving behaviour which characterize the ordinary functioning of the individual." (p.499). There is an implication here that there are degrees of inability to cope during crises and this would fit with Auerbach's emphasis on individual differences in dealing with crises (1983).

A measure of the confusion about definition of crises that has existed in the past, was revealed in one of the rare studies to attempt to delineate the hallmarks of a crisis. Bloom (1963) asked eight mental health professionals to react to 14 mini case histories of stress experiences and in only five of the 14 case histories were there unanimous decisions as to whether the situations constituted crises or not. No further studies in this area appear to have been performed to test Bloom's findings.

Since Caplan's pioneering efforts at crisis theory formulation, crisis intervention programs have grown faster than has crisis theory. Nevertheless, crisis theory discussion continues to surface. One of the areas of debate has been that of parenthood and subsequently, prematurity.

Crisis Theory and Prematurity

Prematurity as a Crisis for Parents

Early theorists like Bibring (in Choi, 1973) and more recent ones (Selby et al., 1980) see first time motherhood as a developmental crisis. Shainness (1963) sees labour and delivery as an additional "acute crisis" over and above that of pregnancy. Jeffcoate et al. (1979) on the other hand, suggest that parenthood as such need not necessarily be a crisis, but can develop into one in such circumstances as prematurity. Kennell and Klaus (1982) go further, stating that prematurity in general constitutes a "severe crisis". They do not, however, give their rationale for this statement. Nor do Caplan et al. (1965) when they refer to prematurity as an "acute crisis". These authors go on to say that the severity of the crisis of prematurity likely depends not only on the danger to the babies' lives but also on the degree of unpreparedness of their parents.

It would seem logical to expect the parents of VLBW premature babies to react with crisis behaviour to these infants' births because of the danger to their survival that the extreme immaturity of their vital systems poses. Minde et al. (1980) have described VLBW prematurity as a "severe crisis", though without presenting a theoretical basis for their statement. In the light of their study comparing fullterm parents with parents of VLBW premature babies, Jeffcoate et al. (1979) propose that individual family members may experience prematurity as a crisis according to the extent to which one sees the situation as a threat to personal status, goals and objectives. The authors see these aspects of premature mothers' identities being more strongly threatened than those of fathers because maternal caretaking roles have to be performed by professionals for several weeks after delivery, with mothers reluctantly playing an ancillary role.

The Concept of Mothers' Four Psychological Tasks

Caplan et al. (1965) have contributed valuable insights into mothers' reactions to premature birth, setting them within a crisis theory framework. Their contributions are derived from four studies of parents of premature babies of various birthweights, which they conducted between 1954-1962. The 86 families they studied represented black and white populations and lower and middle-class socioeconomic strata. From their studies, the authors developed a proposition which states that there are four psychological tasks which confront mothers of premature babies which they need to perform if they are to come through the crisis of prematurity successfully and develop a positive relationship with their babies.

The first task faces mothers at delivery. They must withdraw the emotional attachment to their newborns that had begun to develop during pregnancy, so as to avoid the deep pain their babies' possible deaths would cause them. At the same time, these mothers hope the babies will live. This self-protective process is referred to as "anticipatory grief". The term originated with Lindemann (1944) to describe a grieving process among those close to men who had left to fight in World War II; the process related to mourning the possible deaths of the men.

Simultaneously with the first task, mothers must perform the second task, which entails facing and accepting their feelings of failure at not having delivered fullterm normal babies. To perform the third task, mothers must resume the process of relating to their babies which was interrupted by anticipatory grief. This resumption characteristically occurs when a particular change leads mothers to believe their babies will live, such as a change in appearance or a more positive attitude in a nurse. Finally, the fourth task requires mothers to understand how premature babies differ from fullterms with regard to special needs and initial atypical growth patterns, but also to realize the special needs are only temporary and in time their babies will develop according to general patterns. In the opinion of the authors, mothers need to perform the third and fourth tasks before their babies leave hospital in a period that could range from 2-10 weeks postpartum.

The notion of the necessity for mothers to complete the four tasks to successfully weather their crises of prematurity, has received limited attention from researchers. Kennell and Klaus (1982) believe mothers

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need not experience anticipatory grief if given contact with their babies in the first hours of life, as well as extra support from hospital staff. While these measures can ease mothers' suffering, they cannot save critically ill infants from their struggles to live nor their parents from their very natural "withdrawal-hope conflict" (Roberts, 1977). Barnard (1982, p.159), commenting on the Kennell and Klaus statement, in the same text points out that even if mothers are saved from experiencing anticipatory grief, they must still face their failure to have fullterm babies and they must also work through tasks three and four if they are to accept their babies and help them grow into normal childhood.

Commenting after Barnard, Minde (Kennell and Klaus, 1982, p.159) states that women today do not have as great a sense of failure about having premature babies as did their counterparts 20-30 years ago. There may be some grounds for this statement since the women's movement may have helped many women express their identity in other areas besides motherhood, instead of it being the main source of their sense of worth as in the past. Nevertheless, there are still many women today who see motherhood as the preeminent expression of their female identity and who see this personified in a "bonny, bouncing" newborn.

The concept of the four psychological tasks was developed in the 1960's when fathers were still assumed to have only peripheral affective investment in their babies. Consequently, Caplan et al. (1965) studied only the mothers of premature babies. However, Minde (in Kennell and Klaus, 1982, p. 159) observes that fathers of premature babies face similar issues to mothers in terms of the four tasks. Roberts (1977) goes further, stating that fathers go through the same stages as mothers, though the pace may differ. There may well be a difference in the degree of intensity of feeling with which each spouse works through the four tasks. After all, the spouse who has carried a baby as part of her body for months, is more likely to feel a keener anguish at possibly losing that baby than the male spouse who was not so physically and emotionally involved with the baby during pregnancy. This statement would only be true, of course, in cases where mothers felt positively toward the fetus and looked forward to having the baby.

The only study to investigate the occurrence and extent of performance of the four tasks in mothers of VLBW premature babies, has been conducted by Silcock (1984). Using records, interviews and home visits, she studied maternal struggling with the tasks in the families of 24 infants, as well as the outcomes in terms of infant development and the evolution of mother-infant relationships from delivery until the babies were 16 weeks old (age adjusted for prematurity).

Silcock (1984) found a wide diversity of accomplishments on the four tasks with a number of factors playing a part, but overall, 10 mothers were highly or moderately successful and 14 were unsuccessful.

The hallmarks of the latter mothers appeared to be their lack of awareness of the tasks to be performed, and the fact that they had suffered less physically and psychologically from premature delivery and had had less sick infants. Of the 10 more successful mothers, four were nurses and two were doctors and Silcock surmises that their professional knowledge of the hazards to their babies' lives may have caused them more intense suffering than parents without that knowledge. They were old mothers, four of them being in their 30's and for two-thirds of them, it was their first delivery. Six of them had a history of infertility and miscarriages. They may therefore have had particularly strong investment in working through the four tasks. All had completed high school and some had postsecondary education, including university degrees. Half had worked as professionals. They were all married to men who were employed, 80% in either skilled or professional occupations.

In contrast, three of the 14 unsuccessful mothers were unmarried although one subsequently married the baby's father. The husbands of the other 11 women were less well educated than those of the 10 successful women, with only 50% being employed in skilled or professional positions. Their employment rate was below 80%. Six of the women had less than high school education and two were 16-year-olds so preoccupied with multiple stresses in their lives, that they had little interest in their babies. A similar situation applied to a

30-year-old immigrant woman living in a rural area with three other small children to care for apart from her hospitalized VLBW premature baby. A final characteristic of these mothers, was that 9 out of 10 lived close enough that they could have visited their babies daily, but only 2 did so.

An important overall finding by Silcock (1984) confirms that of Caplan et al. (1965), namely, that maternal efforts to perform the four tasks were predictive of their future maternal care patterns. Silcock found that successful performance was related to better mother-infant relationships when infants were 1 month old (age adjusted for prematurity) and to superior mother-infant relationships when the infants were 16 months old (age adjusted for prematurity).

Silcock (1984) offers a critique of the proposition concerning the existence of the four tasks and mothers' performance of them. First, she believes that the problems mothers face are more complex than those depicted in the typology. Secondly, her talking with over 400 mothers of VLBW premature infants revealed that many of these mothers do not relinquish their fantasy of the perfect baby they had envisaged, even after completion of task 1, that of dealing with anticipatory grief. Instead, observations and parental reports showed that a number of parents, while appearing to have accepted their VLBW premature infants, continued even 2 years after delivery, to compare these infants

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unfavourably with the hoped for healthy child, or with their fullterm siblings.

Reporting on mothers who experienced a sense of failure, Silcock (1984) states that most of those who experienced intense or even moderate feelings of failure, were unable to relinquish them until they could prove they could carry an infant to term or very close to term. There were 15 such mothers and 12 became pregnant and/or suffered miscarriages within a "short period" of giving birth to their VLBW premature infants. Even among mothers not as strongly affected by feelings of failure as these 15, feelings of guilt and failure tended to surface at a later date and they had to deal with them then. These findings indicate that it is not possible for mothers to work through tasks 1 and 2 in the 10 weeks Caplan et al., (1965) saw as the desirable maximum period.

With regard to task 3, that of mothers resuming the process of becoming attached to their infants, Silcock (1984) notes that internally generated emotions like fear and denial and external factors such as geographical distance, child care problems and transport difficulties, resulted in a number of mothers making infrequent visits to their hospitalized babies.

Finally, Silcock (1984) agrees with several studies which show that it takes some mothers years, not a mere 10 weeks, to perform task 4, requiring their realization that their babies' special needs are only temporary and in most cases, will fade in time into more normal developmental patterns. The studies show that a number of mothers appear to be overprotective toward their VLBW premature children, or evaluate them more negatively than their peers, until the children are well into their preschool years (Bidder et al., 1974; Boyle et al., 1977; Jeffcoate et al., 1979).

Summary

The foregoing has been a discussion firstly of crisis theory in general and secondly, a limited examination of the efforts by Caplan et al. (1965) to develop a theory of prematurity as crisis, together with responses their propositions have evoked from other investigators. What follows is a presentation of studies concerning parents' reactions to the births of their VLBW premature babies. Several of the studies contain information and analyses that are useful in helping to further explore the notion of prematurity as a crisis and in developing more effective methods of helping parents understand and work through the experience as positively as possible.

The Experiences of Parents of Premature Babies

Pregnancy

During pregnancy, mothers may have experienced warning signals of a premature pregnancy such as bleeding, pain or loss of fluid from the sac surround the fetus (Kaplan and Mason, 1960). Prepartum problems suffered by the 33 mothers Lissenden (1984) interviewed, included hemorrhaging, rupture of membranes and high blood pressure.

Some mothers' problems may necessitate their admission to hospital up to 3 months prepartum. This may jolt their confidence with regard to their maternal role and when they realize their families are coping without them, their morale may be further affected (Kaplan and Mason, 1960). Delivery of their babies does not boost their morale but in many cases comes as a shock. This was the case for most of the 33 mothers and 16 fathers whom Lissenden (1984) interviewed. For no matter what prepartum problems mothers may have, they hope to carry their babies to term (Kaplan and Mason, 1960).

Delivery

Premature mothers' experience of giving birth is very different to that of fullterm mothers. For mothers with no serious pregnancy complications, there may be a last-minute rush to the hospital since they may have entered early labour without recognizing the symptoms (Roberts, 1977).

On arrival at the hospital, they will be aware of a sense of urgency and concern among the staff, expressed in worried looks and discussions in hushed tones (Roberts, 1977). Constant fetal monitoring may increase mothers' worry that their babies' lives are in jeopardy (Kaplan and Mason, 1960). Mothers may not understand medical explanations concerning the premature birth process and related drug therapy (Lissenden, 1984). A caesarean section may be necessary. Where delivery is vaginal, labour is usually easy and fast because of the baby's small size (Dubois, 1975), but the newborn may not give that first cry for which parents listen expectantly (Roberts, 1977).

After delivery, the staff talk in quiet tones among themselves (Dubois, 1975). Those babies not born in a tertiary hospital are rushed to one immediately after delivery and it may be about 5 days before their mothers see them (Marton, Minde and Perrotta, 1981) although it can be longer for geographically distant parents. Usually parents will have been encouraged to see their babies before transportation and to touch them if possible, but the contact is, of necessity, brief.

Fathers may or may not have been present at delivery but Oakley (1979) states that childbirth can be as physically and emotionally draining for fathers as for mothers. Of the 33 mothers Lissenden (1984) interviewed, 14 stated that their babies' fathers were present during childbirth, while 9 stated the fathers waited outside the delivery room. Five of the mothers had caesarean sections but Lissenden does not say if any fathers were present during this procedure.

In their interviews with a group of parents of premature infants Jeffcoate et al. (1979) learned of the impact on them of the unexpected labour and delivery. For 7 of the 13 fathers and 11 of the 17 mothers, the timing of their babies' births was totally unexpected. Six of the fathers and 12 of the mothers experienced great anxiety during labour and delivery, with 3 fathers and 3 mothers feeling mild anxiety. The total intrapartum experience was "shocking and upsetting" (p. 140) for the parents. Lissenden (1984) comments that the birth of a VLBW premature baby is frightening even to parents who previously had had a heavier premature baby and were not expecting a subsequent baby to be born so soon. The fathers she interviewed were in such a state of shock at the unexpected birth of their infants, that only 4 of 14 fathers who visited their newborns in the NICU could remember any of the information they had received from doctors when they visited their wives later.

The early gestational age of VLBW premature babies is reflected in their appearance. They are tiny. Their heads are large in comparison to their trunks, their extremities are long, they have not developed a fat layer and so they appear scrawny (Goldberg and DiVitto, 1983). It is therefore understandable that parents react negatively at the first sight of their unusual babies. The parents interviewed by Lissenden (1984) were appalled by their infants' smallness which left a strong impression. Blake et al. (1975) report that "almost all" the 160 mothers of VLBW premature infants they talked to, experienced very mixed feelings at first sight of their newborns. There was disbelief, hatred, a wish the baby would die, all followed by shame and guilt at not feeling immediate love for their babies as socially expected. Several mothers worried about the possible harmful effects their initial negative feelings might have on their babies. Most of the 13 women Cramer (1982) interviewed, reported a sense of unreality, feeling that birth had not really occurred. Equally sad, though less dramatic, were the findings of Jeffcoate et al., (1979) who found 25 of 30 parents of fullterm newborns felt proud and happy immediately following delivery, with the remaining 5 feeling neutral, whereas 13 of 30 premature parents felt ambivalent or neutral and 8 felt extremely anxious.

The Early Postpartal Period

Parents of VLBW premature infants can now usually see their newborns for the first time within minutes of delivery, except for mothers who delivered by caesarean section and who have to wait 1-24 hours (Yu, Jamieson and Astbury, 1981). However, most of these parents are denied the anticipated joy of holding their babies at their first meeting, an experience all parents expect. Of the 33 mothers Lissenden (1984) interviewed, only 21 saw their newborns in the delivery room. A fortunate 4 held their babies for a few seconds, while a further 6 touched their babies' fingers and toes as they lay in the transport incubator. Twelve mothers, including 5 who had had caesarean sections, neither saw nor touched their babies in the delivery room, and all regretted this.

Anticipatory grief. Aware that their babies are in the NICU to receive treatment for life-threatening conditions, many parents may experience anticipatory grief. According to Silcock (1984), of the 24 mothers in her study, 7 had mild symptoms, 5 moderate symptoms and 12 experienced intense anticipatory grief. Of these 12, 6 were medical professionals fully aware of the health hazards their babies faced. As well, for two-thirds of these mothers, their VLBW premature babies were their first babies. Unfortunately, Silcock does not identify the thoughts, feelings and behaviours which in her view are manifestations of anticipatory grief.

The studies by Benfield et al. (1976) and Yu et al. (1981) are the only two to operationalize the concept of anticipatory grief. In the project of Benfield and team, anticipatory grief was measured by seven items: anger, guilt, irritability, sadness, preoccupation, loss of appetite and difficulty in sleeping. On the day of their infants' discharge, 101 sets of parents were asked to complete a questionnaire concerning their emotions and behaviours since their babies' births. The parents were predominantly white and middle-class and all lived geographically distant from the tertiary hospital. All parents had had high-risk newborns, 40% of whom weighed 2,500 grams or less at birth. No gestational ages were given for these babies.

On analyzing the questionnaires, the team found that significantly more mothers than fathers reported feelings of sadness, guilt, anger and loss of appetite. In 61 instances, a mother's total score exceeded that of her husband. The authors speculate that the differences between the sexes in reported feelings may be due to the traditional willingness of women and unwillingness of men to discuss feelings.

Yu et al. (1981) also studied parents of high-risk infants. They asked 20 parental couples to complete questionnaires concerning their feelings and behaviours during the first 2 weeks following their babies' births. They furnish no demographic data on the parents but from information they give on the infants, it appears that 10 of the infants were VLBW premature babies. They used all seven of the criteria used by Benfield et al. (1976) to measure anticipatory grief, but added two more, disinterest in work and hopelessness.

Sadness and difficulty sleeping were the symptoms parents experienced most frequently. Mothers suffered seven of the nine symptoms more often than fathers did. In particular, they experienced loss of appetite twice as often as fathers and guilt feelings more than twice as frequently as fathers. The only behaviours fathers exhibited more than mothers were irritability and disinterest in work.

On the whole, the findings of Yu et al. (1981) support those of Benfield et al. (1976). It is true that the data from the two studies refer to different temporal dimensions and that one set of data was presented in the form of global percentages and the other in the form of frequencies. It is also true that the criteria for indicating the seriousness of the infants' problems and of anticipatory grief experienced by the parent, overlap only partially. Nevertheless both groups of investigators found that anticipatory grief as they measured it, does not appear to be related to the severity of the infants' illnesses.

A problem with both studies concerns the fact that the behaviours designated as symptoms of anticipatory grief, inadequately reflect this emotional state, originally defined by Kaplan and Mason (1960, p.543) as "a [mother's] withdrawal from the relationship already established with the coming child so that she still hopes the baby will survive but simultaneously prepares for its death." This definition emphasizes an emotional seesaw between hope and grief which is not represented in the symptomology employed in the two studies.

Even while mothers experienced anticipatory grief, they may have to deal with other negative emotions as well, as may fathers.

Parents' feelings of failure. Mothers of VLBW premature babies are usually disappointed at having delivered premature babies since women hope that every pregnancy will produce a healthy baby. In addition, the baby's birthweight is seen as a mark of the mother's achievement only if it closely approximates the average (Oakley, 1979). Mothers of VLBW premature babies have attained neither of these goals. As a result, researchers have noted that many of them experience a sense of failure at having delivered infants who do not measure up to their own expectations and those of society.

Cramer (1982) found a sense of failure to be the most common reaction in the 13 women he interviewed. They reasoned that because their pregnancies had been incomplete, their babies were therefore incomplete and so they, as the mothers, were also incomplete. They saw their defective babies as reflecting their own defectivenss and consequently suffered a diminution in self-esteem. Jeffcoate et al. (1979) report that "several" fathers and mothers in their study felt they were failures for a different reason. They saw themselves as being unsuccessful in their reproductive roles by producing infants who did not meet the social criteria for normality.

On the other hand, Kaplan and Mason (1960) point out that not all mothers delivering VLBW premature babies have a sense of failure. They cite as an example those women who have had repeated miscarriages and so are only too relieved that they have delivered a live baby. Similarly, nine mothers in the study by Silcock (1984) felt no sense of failure. Three of them had had such difficult pregnancies that they felt proud of having given birth to a live baby.

Mothers' feelings of guilt. Along with experiencing a sense of failure, many mothers of premature babies agonize as to their possible role in precipitating premature labour. Klaus and Kennell (1982, p.216) describe this as a "universal and normal reaction". Others writers see the process as motivated by a sense of guilt that prompts explanations of varying approximations to medical accuracy (Selby et al., 1980). Some mothers may blame premature delivery on their having gone on a particular outing (Shosenberg, 1980a). Almost all of the 13 mothers interviewed by Cramer (1982) felt guilt and some saw premature labour as a punishment for such "wrongdoing" as having too frequent sexual intercourse, drinking too much on a particular occasion, and smoking. Enjoying a job or feeling inadequate were further reasons given by the mothers for onset of premature labour. While being aware that drinking and smoking are factors known to be associated with prematurity, Cramer believes their incidence among the mothers was low and had been blown out of proportion by their guilt feelings. Some mothers attempted to transfer these guilt feelings to husbands, doctors and nurses, accusing them of misdeeds that had caused the onset of premature labour.

Parental depression. Depression is a further emotional reaction that begins to emerge in the early postpartal days in both parents of VLBW premature neonates. Mothers must deal not only with the depression arising from having had a very frail baby, but also with the commonly experienced "postpartum blues". Klaus and Kennell (1982) state that doctors and nurses in the United States have reported that well over 80% of women suffer postpartum depression with crying episodes during hospitalization. They further state that "many" mothers report extreme depression with sadness, crying and inability to get out of bed. A group of mothers who are perhaps susceptible to the most intense depression are those whose VLBW premature babies were delivered by caesarean section. Klaus and Kennell describe mothers in general who have given birth by this method, as sharing a common depression due to the necessity for surgery, the postoperative pain and their failure to have a vaginal delivery.

In comparing postpartum depression in parents of fullterm and VLBW premature babies, Jeffcoate et al. (1979) state that half of the 12 depressed mothers of fullterm babies experienced that state beyond the first week postpartum, whereas 15 of the 17 mothers of VLBW and other premature babies felt depressed for longer than 1 week. The authors do not state how many mothers delivered by caesarean section. Only 1 fullterm father was "sad or depressed" and then for only a "short time". In contrast, 8 of the 13 fathers of premature babies had similar reactions, 3 of them experiencing depression for longer than a week.

It is regrettable that the authors did not give a breakdown of their findings by categories of prematurity to show whether or not parents of VLBW premature infants experienced more and longer periods of depression than those with less premature babies. It is also noteworthy that Klaus and Kennell (1982) considered sadness to be a symptom of depression, while Jeffcoate et al. treat them as separate emotional states.

Some authors point to specific reasons why parents of sick premature babies may feel more depression than other parents. The uncertain outlook for their babies' survival may cause parents to vacillate between hope and depression (Roberts, 1977) while parents' personal situations may be a further cause of depression. Newman (1980) states that some of the 10 mothers in her study experienced two situations which they believed induced some of their depression in the first 3 weeks postpartum. The first situation related to the difficulty they had trying to explain to relatives the nature of their babies' physical problems when they themselves were not sure about them. The second problem faced by some mothers related to the fact that they felt they had no close friend or relative they could talk to about their feelings concerning their premature motherhood.

Parental responses to infants' degree of prematurity and physical condition. Depression is also one of the emotional responses of some parents to the degree of prematurity and severity of illness in their infants. In interviews with 20 mothers which she conducted 3-5 days postpartum, Choi (1973) found that the lower the infants' birthweights and the lower their gestational ages, the higher were the levels of mothers' depression and anxiety. There were no equivalent reactions among mothers of fullterm neonates.

Other studies with a similar focus report contradictory findings. Jeffcoate et al. (1979) state like Choi (1973), that "many" of the parents with the most premature babies of the 17 they studied, felt extreme anxiety and fear about their babies' physical condition and progress.

On the other hand, Wright and Zucker (1980) present some unexpected findings from their study of 31 couples with high risk babies, 25 of them prematures. Parents did not appear to experience negative emotional responses with regard to the degree of prematurity of their babies and in fact, parents looked significantly more at their lower birthweight, lower gestational age infants, independent of their medical conditions. However, the mothers of infants with low Apgar scores reported fewer negative feelings and less concern about their babies' physical conditions in the later neonatal period, than in the early neonatal period. In contrast, fathers were more worried and reported more anxiety and fear than their wives when their babies experienced medical difficulties. The authors surmise that these mothers' seeming lack of concern about their infants' health may be an expression of denial arising from their feelings of failure at having delivered abnormal babies.

The findings of Yu et al. (1981) show yet other variations. They could discern no differences in the quality of relationship between parents and their babies with birthweights of above 1,500 grams, as compared to those between parents and babies whose birthweights had been below 1,500 grams. With regard to the effect of the infants' medical status on their relationships with their parents, the authors found no differences between the relationships of parents and infants on assisted ventilation and those of parents and infants who did not need such assistance.

With regard to the relationship between parents' feelings and their infants' medical condition, it is difficult to compare the findings of Wright and Zucker (1980) with those of Yu et al. (1981), since the two sets of researchers used different criteria to define the medical status of premature infants. Nevertheless, both their findings and those of Jeffcoate et al., (1979) seem to indicate that many parents feel the beginnings of attachment to their sick babies very soon after birth.

Parents' first feelings of love for their babies. Apart from the above three studies, however, there is little information available concerning the manner and time frames within which parents first feel love for their VLBW premature babies. According to one study, parents vary in the pace at which they come to feel love for these babies. Jeffcoate et al. (1979) report that while 14 of 17 fullterm mothers felt love for their babies in the first 24 hours after birth, 8 of 16 mothers of premature babies stated it took 2 months or longer for them to feel loving toward their infants. For some, it was a gradual, overall process, while other mothers felt closer to their infants when they began to display increasing sociableness. The situation was different for fathers. Most fathers of both fullterm and premature babies said they felt love for them in the first few days, although 3 of the 12 fathers of fullterm babies and 5 of the 13 fathers of premature babies needed 2 months and more to develop feelings of love for their babies. Several fathers worried about their wives' inability to feel affection for their infants and one wife persistently asked for her premature baby to be adopted.

Mothers' homecomings without their infants. Whatever quality of feeling parents may have for their newborn, a mother's discharge from hospital is usually a happy event for both spouses. Not only can they proudly show their new family member to their relatives and friends, but they, their other children, if any, and their new baby can settle into a stable routine. The situation for parents of VLBW premature babies is very different. Mothers must come home without their babies and they and their spouses know they face a long and stressful separation from their hospitalized babies. Very few studies have described the feelings of parents about this situation. Newman (1980) states that the 10 mothers she interviewed reported feeling depressed at having to go home without their babies. The mothers studied by Lissenden (1984) were even more deeply affected. She states that the majority of the 33 mothers she talked to felt a deep sense of grief at having to leave their babies in hospital. Almost half related that their distress had been so great that they were unable to remember the instructions about breastfeeding they had received on their discharge.

Parents and Infants in the NICU

Parents of premature infants and parents of VLBW premature infants in particular, have to face the fact that their babies are going to have a far longer stay in hospital than fullterm neonates. According to Marton, Minde and Perrotta (1981) the average stay of infants in their NICU is 6-7 weeks.

Visiting their babies for those many weeks, is a complex experience for parents. They come to know the joy of starting to build a relationship with their babies, and to watch their gradual improvement. On the other hand, they face two major sets of obstacles. One set relates to the anguish they must undergo as they watch their babies struggle to survive, while trying to understand the physiological and technological factors involved in the efforts to help them. The second set of obstacles relates to the delays they must endure before they can enjoy the typical landmark experiences of parenthood, such as the first physical and visual contacts with their very immature infants.

Parents' experience of the NICU environment. Professionals acknowledge that the hectic and complex environment of the NICU offers parents little comfort as they experience the vicissitudes of visiting their babies. Zeskind and Iacino (1984, p.1881) describe the NICU as "intimidating" while Kennell and Klaus (1982, p.195) comment that parents may initially find it a place of "great tension" capable of furnishing "frightening surprises."

Very few researchers have obtained parents' views about the NICU. Newman (1980) reports the comments of only the 10 fathers in her study. On the whole, the fathers seemed very much at home in the NICU. They seemed impressed by the advanced technology and had a sense that purposeful work was in progress. Newman unfortunately does not give any demographic data on the parents in her study, stating only that they were a homogeneous group. Judging by the sophistication of both the concepts expressed by the fathers and the quality of their language, they appear to be drawn from the middle and upper middle class strata and so possibly felt more comfortable in a complex professional environment than less sophisticated parents would.

Unlike the fathers quoted by Newman, 24 of the 33 mothers interviewed by Lissenden (1984) did not place much faith in the technology of the NICU. They feared that the treatments their babies were undergoing were so drastic that they would not survive them. Similar qualms about the NICU technology were expressed by 14 of the 38 parents participating in the study by Yu et al. (1981). They failed to retain the information conveyed to them about the equipment used on their babies. While this could have been due to information overload following explanations about other aspects of the NICU's functioning, the authors report that, despite repeated explanations about the equipment, parental anxiety remained.

To help parents feel more at ease while visiting their babies in the NICU, hospitals have adopted various practices. Newman (1980) describes those in an urban American hospital. Parents can visit anytime and on their first visit, they are shown how to scrub up, are given gowns and taken to their babies whom they are encouraged to handle despite their attachment to various items of equipment.

In a Melbourne hospital, Yu et al. (1981) emphasized explanation and discussion as part of an orientation program for parents, and in their study, they gauged the extent to which parents later recalled information that had been imparted to them. Four areas were explained to parents, the first relating to the equipment used to treat the babies. The other three areas concerned the general appearance and condition of the babies in the NICU, visiting policy and finally, handwashing and infection control policies. All 38 parents remembered the information on area one, 30 recalled the information on area two and 27 remembered the facts concerning area three.

The efforts by hospital staff to explain hospital equipment, rules and procedures may alleviate some of the apprehension parents feel in strange new surroundings. However, there is little the staff can do to shield parents from the emotional upheavals they experience during their babies' treatment in the NICU.

Parental anxiety. Responses on questionnaires from 91 parents studied by Harper, Sia, Sokal and Sokal (1976) indicate that parental anxiety was at a high level during their premature infants' hospitalizations. It was about equal for each spouse and reached its peak when the parents first learned of their babies' conditions. By the time they paid their first visits to their babies, some of the parents felt more reassured since only 44% had feelings of anxiety at that point. Many parents paid frequent and lengthy visits to their infants, performing numerous caretaking activities, although 43% felt ill at ease or anxious doing so. The investigators wonder why these parents continued to visit their babies despite their high anxiety levels. They offer as a possible explanation, the fact that 85% of the parents believed that holding their babies made them feel loved and secure while 44% of the parents believed the quantity and quality of care given to their babies improved when they were present. The authors also speculate that perhaps anxious parents visit more often or alternatively, that as parents get to know their babies better, they increasingly feel them to be part of the family and it is appropriate to feel anxious about the health of a sick family member.

The authors finally comment that it is not clear to them if contact produces anxiety or if it is anxiety that spurs parents to increased contact with their sick babies. Yu et al. (1981) pose the same question. The 38 parents they studied experienced the many emotions associated with anticipatory grief but nevertheless 72% would have resented restricted visiting hours and all felt reassured with repeated visits to their babies. In contrast to the parents Harper et al. (1976) studied, only 5 of the parents interviewed by Yu and associates felt the quality and quantity of care given to their babies improved when they were present. This difference may be due to the extra effort the researchers report making to help parents strengthen their belief that their babies belonged to them and not to the NICU. As well, they encouraged parents to be active in caring for their babies since they were aware many parents felt inadequate at being able to do so little for their sick infants. Twenty-seven parents believed their babies enjoyed the contact with them and felt more loved and secure.

These rewards may well have outweighed the costs of frequently visiting and seeing their very ill babies but the authors hint that for some parents, daily visiting may be a self-imposed ritual where even occasional non-adherence causes feelings of guilt. On the other hand, Silcock (1984) states that from her experience, daily visiting appears to be more beneficial for parents than more widely spaced visits.

The development of parent-infant attachment. To some extent, the emotional strain imposed on the parents of hospitalized VLBW premature infants is offset by the rewards of getting to know their babies during their stay in the NICU. The relationship between parent and infant begins to develop as parents begin to establish verbal, tactile and visual contact with their babies and to perform caretaking tasks for them. However, these parents usually have to wait longer than fullterm parents before they can begin to interact with their infants and for some, the initial attempts are often stressful.

Jeffcoate et al. (1979) report that the parents of premature babies in their study saw, touched and held their babies significantly later than did fullterm parents, while other researchers noted the apprehension of some parents when they first approached and touched their VLBW premature infants. This was the case with some of the parents interviewed by Lissenden (1984). One mother needed the encouragement of the nursing supervisor before feeling confident enough to touch her baby the first time. Some of the 20 mothers in the study by Silcock (1984), while wishing to become close to their babies, were also afraid at first to touch them.

During their observation of 18 mothers and their VLBW premature babies in the NICU, Minde et al. (1978) noted that during their first and second visits, mothers appeared reluctant to actively relate to their infants and limited themselves to looking at their babies. This was despite the explicit encouragement of NICU staff to touch their babies during their first visit. The authors offer as possible reasons for this behaviour, the mothers' need to first become used to their babies' unusual appearance and perhaps the further need to complete their mourning for the normal child they had hoped to have, before they could accept their premature baby.

In earlier observations in the NICU, Minde, Ford, Celhoffer and Boukydis (1975) studied the interaction between 3 randomly selected mothers and their VLBW premature babies in the immediate postpartal weeks. These mothers and their spouses were interviewed before they began visiting their babies and mothers K and R appeared more positively inclined toward premature parenthood than did mother C. She was 18 years old, had married 3 months before her baby's birth and neither she nor her husband wanted the baby. In addition, she had come from a large family with a poor parenting history. With each weekly visit, both mothers K and R decreased the amount of time it took for them to start talking to and touching their babies, whereas mother C paid minimal attention to her baby on her first visit which she paid at the request of the hospital, and only returned 4 weeks later for her second visit. The authors do not report her behaviour during her second and subsequent visits.

Minde et al. (1975) sensitively describe a sequential pattern in mothers' touching behaviours. In early visits, they only touched their babies' heads and extremities. Only after several visits did they practice more extensive touching such as lifting parts of their babies' bodies or placing their hands under their babies' backs or abdomens. The tentativeness of these mothers is understandable in view of their babies' fragility and attachment to mechanical apparatus, so it is likely they may have felt the need for extra time to feel confident handling their babies under such abnormal conditions.

Parents' caretaking activities. Caretaking enabled parents to practice more comprehensive physical contact with their babies and many found the experience a rewarding one. Of the 38 parents in the study by Yu et al. (1981), 34 of them were observed enjoying many activities with their babies during the first 2 weeks postpartum. Parents spent the same amount of time on caretaking tasks with the exception of diaper changing, which mothers performed significantly more often than fathers.

Some of the contact behaviours of the 91 parents who completed questionnaires for Harper et al. (1976) were similar to those reported by parents to Yu et al. (1981). Touching their babies was performed by 92% of mothers and 95% of fathers, while 83% of mothers and 82% of fathers held their babies. Eighty-three percent of mothers talked to their babies, as did 79% of fathers. Once again, the number of mothers changing diapers far exceeded the number of fathers: 51% as opposed to 29%. Other activities parents engaged in with their babies included rocking, feeding, and singing.

Caregiving activities enable parents to develop a sense of competence in a situation where they have initially had to allow others to take over their parenting role. In the case of the Brisbane hospital described by Lissenden (1984), shortly before their babies' discharge, parents had learned to bathe, help gavage feed and breast- or bottlefeed them. Most tertiary hospitals now encourage these parental achievements.

Parents' first experiences of infants' eye openings and smiles.

Even while caregiving, parents of VLBW premature infants have to wait a comparatively long time for the first all important visual interaction with their babies. Kennell and Klaus (1982) state that at first, premature neonates in general have longer sleep periods than fullterm neonates, with only short periods of wakefulness and that parents feel regretful about this situation. Korner (1981) speculates that mothers long for their first eye contact with their babies as a confirmation of these tiny infants' humanness and studies by Cohen and Beckwith (1979) and Marton, Minde and Ogilvie (1981) have shown premature infants' eye-opening to be an impressive elicitor of parental behaviours such as parental touch and talking. The infants' gaze and their parents' positive responses thus set up a mutually rewarding cycle of interaction. Many parents may have to exercise patience before this occurs however. Marton, Minde and Perrotta (1981) found that none of the 12 VLBW premature infants they observed during the first 5 postpartal weeks opened their eyes at all during their fathers' visits, and only had their eyes open for 3% of the time during their mothers' visits.

The parents of VLBW premature infants also have to wait longer for their babies' first smiles than do other parents. According to Goldberg and DiVitto (1983), fullterm babies display social smiles around 6-8 weeks of age and the little research done with premature babies to date, indicates that they tend to start smiling around term plus 6 weeks. As a result, parents of VLBW premature babies, many of them born at 30 weeks gestation and less, face a wait of months and not weeks before they are rewarded with their babies' first smiles. For instance, babies born at 28 weeks gestation will first smile about 18 weeks after birth (Blake et al., 1975).

Sex roles in the NICU. A study by Marton, Minde and Perrotta (1981) is the only one that has fathers' roles in the NICU as its main focus. Observations of 12 couples from assorted ethnic and socioeconomic backgrounds revealed that when visiting their babies together, spouses' activities with their babies were very similar except for physical caretaking tasks which mothers performed more. However, when observed caring for their babies at home after discharge, parental behaviour reverted to social stereotype. In the authors' opinion, the similarity of spouses' activities in the NICU occurred because of the unique circumstances prevailing there; the environment was equally unfamiliar to both parents, opportunities were equally available to each to interact with their infant, such acts were voluntary and pressures to conform to social stereotype were absent.

The fact that mothers did more physical caretaking than fathers somewhat weakens the authors' argument that sex-typed behaviour was absent during joint visits, since 3 of the 12 fathers did no physical caretaking at all and the reluctance of fathers in general to do so, particularly when related to disposal of body wastes, has been well documented. As previously noted, it was evident in the studies by Harper et al. (1976) and by Yu et al. (1981). So it would appear that parents carry their social conditioning into the NICU where the more androgynous environment modifies their behaviour to some extent.

The findings of Marton, Minde and Perrotta (1981) regarding similarity in non-caretaking parental behaviours during joint visits with their babies, tend to be confirmed by other studies. Yu et al. (1981) observed that both parents spent most time touching, talking to and cuddling their infants, and each parent spent the same amount of time on each activity. Jeffcoate et al. (1979) noted that fathers of prematures began visiting, touching and holding their babies at the same time that mothers did.

Unlike Marton, Minde and Perrotta (1981) who reported that the rate of visiting by each parent was approximately the same, Newman (1980) found that there was variation to some extent in spousal visiting which she attributes to personal factors. Nevertheless she is in general agreement with Marton and associates that the NICU environment provides a certain equalizing of the sexes since both parents have the role of visitor only. It may be that parents set up a ritual when visiting together, in which they implicitly agree to alternate interaction with their baby so as to give each other equal time.

Steps in infants' progress prior to discharge. As parents learn the practices and routines in the NICU, they come to know and anticipate the landmarks of weight gain and improvement in feeding used by medical staff to gauge their infants' progress. Silcock (1984) describes the procedures typically used in a Brisbane hospital.

Infants remain in isolettes until they reach a weight of 1,800 grams and their physical conditions have stabilized. They are then transferred to the recovery nursery when they weigh approximately 1,900 grams and are receiving 3-hourly tube feeds. This is a major psychological breakthrough for parents since their babies are now well enough to be guided to breast- and/or bottle feeding. When the babies are feeding satisfactorily, progressing well and weigh close to 2,200 grams, mothers are invited to room in with these babies for a few days, taking over complete care under supervision. The babies are then discharged and mothers encouraged to bring them back to the hospital at specified intervals for follow-up examinations.

These practices appear to be standard in most NICU's, although there may be slight variations in the weights infants need to reach before they can progress to the next step before discharge.

A measure of the impact on parents of their VLBW premature infants' births and hospitalizations, is revealed by Harper et al. (1976). Of the 91 parents in their study, 76% experienced emotional difficulties with consequences ranging from increased use of tranquillizers to hospitalization for hypertension.

Parent-Professional Relationships

Very few studies have elicited parents' perceptions and experiences of professionals responsible for their babies' care in the NICU. Those in existence present a mixed picture of extremely stressed parents and professionals attempting to work together under conditions of great strain.

Parents and doctors. The 33 mothers interviewed by Lissenden (1984) were critical of physicians on various grounds. More than half the mothers either misunderstood or could not understand explanations from doctors regarding the physical conditions that precipitated their premature motherhood. A further three mothers were too ill to absorb the doctor's words.

Mothers were confused by the jargon used by doctors and this may have contributed to their misunderstanding. In addition, mothers worried when doctors used phrases like "termination of a pregnancy" which they interpreted as ending the fetus's life. Mothers also expressed their need to have explanations repeated several times before they could fully understand the information being conveyed to them.

Finally, these mothers felt frustrated when doctors told them their babies would need stimulation after arriving home, but never spoke to them further regarding what they meant by stimulation and how mothers should go about providing it.

On the other hand Kennell and Klaus (1982) present details of a paediatrician's discussion with a couple, the Dixons, who described what behaviours by doctors and nurses had been most helpful to them. They appreciated being able to call the NICU at any time and have nurses answer questions and provide explanations in a kindly manner. The Dixons found these contacts invaluable sources of reassurance. For Mr. Dixon, it was the paediatrician's presence and encouragement to touch his baby on his first visit to the NICU, that enabled him to believe he could survive that and the other experiences of premature fatherhood. Similarly, he felt psychologically strengthened after talking to the paediatrician about his fears that his baby might die and that he and his wife might not recover from that loss.

Other parents also reported satisfactory experiences with hospital professionals. Only 7% of the 58 families in the questionnaire study by Harper et al. (1976) expressed dissatisfaction with the professional NICU staff.

Mother-nurse relationships. There is very little research relating to interaction between parents and nurses in NICU's, but several writers have commented on various aspects of mother-nurse relationships. What emerges is a picture of intricate emotional interplay.

Silcock (1984) stated that "a few" of the 24 mothers she interviewed resented the nurses' efficient care of their babies, especially as they knew their babies' lives depended on it. The 13 mothers interviewed by Cramer (1982) expressed similar ambivalence. They were grateful for the skills of the nurses but felt inferior because the nurses could look after their babies better than they could.

Prugh (1953) suggests the possible origins of some mothers' negative relationships with nurses. In a steplike progression, mothers' guilt that some omission or misdeed on their part caused premature delivery, induces a sense of inadequacy that underlies these mothers' anxiety about being unable to care adequately for their hospitalized babies. These mothers accordingly come to feel resentment and jealousy toward the trained NICU nurses who have the major responsibility for their babies. These feelings may also lead to mothers' fears that the nurses are competing with them for the affection of the babies. All these negative feelings may contribute to the suspicion and hostility that some mothers display toward NICU nurses.

Field (in Kennell and Klaus, 1982, p.157) comments that some mothers of fullterm children display similar behaviours toward grandparents and teachers of preschoolers but that the situation for many mothers of premature infants is more intense because the specialized knowledge of NICU nurses appears to these mothers to be beyond their own grasp.

Drawing on their years of work in a NICU, Kennell and Klaus (1982) state that some mothers' fears of rivalry with nurses are well founded since nurses often develop close attachment to some of the babies for whom they care. It is in these situations that mutual feelings of jealousy may develop between the nurses and the babies' mothers. Although these many strains may be present in some mother-nurse relationships, there are often times when nurses become mother figures to some mothers. This situations has its own complications.

Nurses firstly act as mothers when they encourage and teach mothers to perform caretaking tasks for their infants (Cramer in Blake et al., 1975). Mothers, particularly primiparous mothers, may also treat nurses as mother figures to meet their need for emotional support and factual guidance during the first trying postpartal months, but may also resent their dependence on them.

This is not the only price nurses may pay for their roles as maternal figures. Prugh (1953) suggests that some mothers' negative attitudes to nurses may reflect the fact that these mothers see the nurses as transference figures who revive early childhood memories and feelings related to their natural mothers, and which the mothers now direct toward the nurses.

Prugh (1953) also suggests that mother are not only worried about their babies' health, but also feel deprived of the joy and challenge of discovering their babies as they watch nurses acting as substitute mothers to them. These mothers may then focus their frustration at their deprivation on NICU nurses, among others.

After the Infants' Homecomings

Once their babies have come home, many parents become aware that several aspects of their babies' functioning differ notably from those of fullterm babies.

Premature infants' atypical behaviours and developmental courses. After two assessments on premature and fullterm babies who had been home 10 days, Goldberg and DiVitto (1983) found that the fullterm infants had become less irritable and the premature infants more so. This was confirmed by Drillien, Thomson and Burgoyne (1980) who noted marked irritability in Scottish VLBW premature infants in their first year of life.

Over the first 4 post-discharge months, Goldberg and DiVitto (1983) also found fullterm infants became less fussy while premature infants became more fussy. At the opposite extreme, the authors note that parents of premature babies worry that their babies cry very little. They speculate that perhaps this is the case because crying takes more energy than immature babies can spare. The result is that they cannot provide parents with clear signals through crying when they need attention (Goldberg, Brachfeld, and DiVitto, 1980). Barnard (in Kennell and Klaus, 1982, p.169) also found that premature babies' cues were less clear than those of fullterms when she compared them at 4 months and 8 months from birthdate. She saw the premature babies' cues as being mainly conveyed in changes in their level of motor activity and in their changes in posture.

These babies' low energy levels may also be the cause of their hypoactivity which has been noted by several investigators and which forces parents to continuously exert themselves to elicit positive responses from the infants. Goldberg et al. (1980) found this to be the case in the babies' first year of life with regard to feedings, face to face play and object play. Crnic, Ragozin, Greenberg, Robinson and Basham (1983) found that the more actively mothers interacted with their babies, the less the babies signalled. They also showed less positive affect and more gaze aversion than their fullterm peers. This mutually unsatisfying mother-child interaction persisted during the first 12 months.

Field (1977) observed 10 premature infants aged 3 1/2 months (age adjusted for prematurity) who had received very low neonatal a priori interactive process scores when tested. These babies showed gaze aversion when mothers engaged intensively in attention getting games but when mother imitated the infants' own behaviour, they exhibited repeated smiling and laughing and less gaze aversion. Field speculates that mothers' continuous attention getting activities may have overloaded the babies' sensory processing capabilities and that gaze aversion may have been the babies' way of pausing to try and interpret their mothers' signals. She suggests that the infants may have enjoyed their mothers' imitative games more because they were observing behaviours already familiar to them and so their underdeveloped information processing abilities were taxed less.

In the only existing study comparing fathers' and mothers' interaction with their hypoactive premature infants, Field (in Kennell and Klaus, 1982, p.168) observed parents playing with premature infants aged 4 months. The fathers were as overactive as the mothers but seemed less upset by the babies' lack of response than were mothers. Fathers smiled, laughed and played infant games more than mothers did and seemed to enjoy their exchanges with their babies more. Field surmises that the differences in spousal behaviour may be due to the fact that fathers were less worried, exhausted and frustrated than mothers because they spent less time with the babies than did mothers.

Several researchers have found that premature infants have a higher incidence of sleep disorders such as difficulty getting to sleep or waking frequently during the night. While these problems may be limited to the early post-discharge period for some babies (Duhamel, Lin, Skelton and Hantke, 1974), Barnard (1980b) states that these problems have persisted for as long as 2-3 years in some infants. She surmises these problems may be due to faulty organization of the babies' central nervous systems as well as to the infants' difficulty in handling sensory input. The latter proposition agrees with that of Field (1977) noted earlier. Barnard's explanations may also account for the tendency of premature babies to be much more restless than fullterms that has been observed by Korner (1981) among others.

Further negative attributes parents may expect to encounter in their infants after they come home, are feeding and breathing problems (Barnard in Kennell and Klaus, 1982, p.180), delayed motor development (Goldberg and DiVitto, 1983) and less vocalizing and smiling than found in their fullterm counterparts (Crnic, Ragozin, Greenberg, Robinson and Basham, 1983).

Parents' three-phase post-discharge experience: a theory. After several years of discussions with parents of VLBW premature infants, Blake et al. (1975) concluded that these parents' experiences after their babies' homecomings can be viewed as occurring in three phases. There is firstly the honeymoon phase, followed by the phase of exhaustion and finally a phase which is characterized by parents feeling more relaxed as they become increasingly competent and successful in responding to their babies' needs.

Phase one The honeymoon phase usually lasts only for the first few days after the babies' arrival home. During that time, parents feel joy and relief that their infants are at last home and the family can begin to return to normal life.

Phase two The exhaustion phase can last a few days or several weeks. Mothers struggle with numerous minor problems in learning to care for their babies, with feeding difficulties often predominant. Mothers feel and look extremely tired and still lack some necessary skills. This description of the second phase appears to err on the moderate side. Among the many burdens parents carry during this periods, are difficulties in meeting their own needs as well as those of family members and dealing with self-doubt regarding their parental competence. These parental concerns were noted first by Kaplan and Mason (1960) who also heard mothers express varying degrees of anxiety and questioning with regard to their babies' capacity to catch up with their fullterm peers.

Later researchers found parents expressing similar concerns. Mothers interviewed by Lissenden (1984) felt unprepared to take over full care of their babies, reporting feeling afraid and even overwhelmed. Jeffcoate et al. (1979) found that while 90% of multiparous mothers of premature babies felt confident about caring for their babies after discharge, only 50% of primiparous mothers of premature babies felt similar self-confidence. Many of these mothers saw their babies as frail and liable to further illness. This perception may have had some basis in reality since some medical staff routinely warn parents that VLBW premature babies are particularly prone to contracting infections and experiencing further illnesses after discharge (Bidder et al., 1974).

Goldberg and DiVitto (1983) point out that parents' loss of self-esteem at failing to deliver fullterm babies may promote anxiety about their ability to make decisions and to question the wisdom of those decisions they do make. They further wonder whether parental anxiety is conveyed to their babies with harmful results. Barnard (in Kennell and Klaus, 1982, p.180) expresses a similar concern, seeing possible harmful effects on both the babies' future development and on parent-infant relationships. While there is no substantive research to indicate to what extent parental worry and self-doubt affect their later parenting performance, many parents show the effects of these emotional states after their babies come home.

Blake et al. (1975) report that many of the parents they talked to were unable to read their babies' cues during the first post-discharge weeks. These mothers were so anxious that they reacted with near panic to most occurrences relating to their babies. As a result, they became exhausted, performed day-to-day tasks with less than their usual efficiency, felt resentful toward their babies and then felt guilty about harbouring this resentment. That this period of mutual adaptation can affect both mother and baby, is shown by Barnard (in Kennell and Klaus, 1982, p.162) who found that 1 month after their infants' discharge, mothers were tired and often depressed while their babies were more irritable than they had been in hospital.

Other studies have shown how stressful the early post-discharge period can be for many parents. Parental reports to Jeffcoate et al. (1979) revealed that many premature parents felt exhausted as they tried to cope with the lengthy delay in their babies' settling into a regular routine. Some 60% of these parents stated that their problems with their babies lasted more than 6 weeks post-discharge and some wondered in despair at various points if they would ever cope. Twenty of 33 mothers informed Lissenden (1984) that they had sought advice in the first week after their babies' discharge. Reasons included difficulty in settling their babies after feeds, extreme crying by the babies at night and their tendency to suffer disproportionately from colic.

Some of these mothers experienced frustration when they sought advice from private paediatricians. In the only study that records parents' experience with private professionals (Lissenden, 1984), parents' comments were critical of paediatricians. Parents were rarely able to see them at short notice and felt that when this was the case, the paediatrician should have referred them to general practitioners or to hospital outpatient clinics where they could obtain advice and help in minor emergency situations. Seventeen mothers receiving home visits from nurses found these helpful.

Silcock (1984) highlights the fact that ecological factors can affect the ability of mothers of VLBW premature infants to understand and cater to the special needs of their babies. Ten of the 24 mothers in her study could not or would not accept the special problems and characteristics of their babies. All these mothers were of lower socioeconomic status. Two of them were immigrant women with limited command of English and additional personal and family problems. Of the remaining 8 mothers, 6 had not completed their high school education and 5 were in their teens.

Phase three According to Blake et al. (1975) when parents enter the third phase of adaptation to having their VLBW premature babies home, mothers feel more confident, and find caring for their babies more rewarding. These mothers feel and look physically better. They now want to talk about their experiences while having and rearing their babies and are particularly keen to talk about their current feelings about their babies.

It would appear that in this phase, mothers feel a personal need to look back and discuss in detail with empathic professionals their total experience to date. Their wish to talk at this particular time may arise from the fact that they now have the energy available, that the professionals are knowledgeable and often understanding about the area of prematurity whereas friends, family and neighbours may not have been, and finally, they may wish to seek assistance in making sense of the complex feelings they have for their challenging babies.

There has been minimal professional discussion of parents' post-discharge experience as Blake et al. (1975) have presented it. There is, however, some information to show that even when parents have mastered their roles of caring at home for their VLBW premature infants, some continue to worry. The mothers interviewed by Cramer (1982) were concerned as to whether their babies would grow into intellectually normal children. Parents in another study worried whether their babies would grow into physically or emotionally impaired children (Duhamel et al., 1974).

Additional stressors affecting parents. Apart from factors directly related to having and rearing their VLBW premature babies, a large number of parents have to deal with stresses arising in other areas of their lives.

Many of the 86 couples interviewed by Caplan et al. (1965) encountered multiple crises unrelated to their babies' premature births. Similarly, a survey of 72 couples by Duhamel et al. (1974) revealed that 80% of them were experiencing moderate to severe psychosocial stress, including conflict and tension in marital and family relations. Preoccupation with these problems may explain why 50-70% of the couples who were financially secure, did not want or fully accept their babies at the time of the survey. Even fully accepting parents can be affected by changes in their environments. Kaplan and Mason (1960) noted that a father's loss of employment or a forced family move had adverse effects on parents' handling of the many stressful situations relating to their babies' births and physical problems.

As facilitator of a Canadian hospital-based support group for parents of premature infants, Shosenberg (1980b) found it necessary to enlist the help of other professionals in assisting some of the couples in dealing with housing, unemployment, psychiatric and marital problems. A number of couples experienced economic strain despite having major medical costs paid by government programs, as the only income for working mothers on maternity leave is derived from unemployment insurance payments.

According to Barnard (in Kennell and Klaus, 1982, p.160), recent research shows that mothers displaying minimal anxiety about their premature babies' conditions, may not be exhibiting symptoms of an emotional disorder, as proposed by Kaplan and Mason (1960) and others, but may be needing to direct most of their energies to dealing with more immediate major problems such as those relating to finances and family relationships.

Of particular concern to many parents, are the reactions of siblings to the birth and presence of VLBW premature infants in the home. Very little information exists with regard to the arrival of a premature baby in the family, much less that of a VLBW premature baby. Yet the emotional and behavioural reactions of older children to the new and special infant often require that parents devote much energy and understanding to dealing with them.

Owens (1960) describes the typical behaviours of two 18-month-old girls after their premature siblings had come home. To convey their wish to again be the babies in their families, the girls displayed such regressive behaviours as again wanting bottles during the night, abandoning newfound toilet habits for diapers only, and reverting to making messes while eating soft foods. Children upset by the birth of a new family member may manifest other regressive behaviours such as bed wetting, thumb sucking, stuttering and baby talk, as well as an increase in such behaviour problems as sleep disturbances and temper tantrums (Trause and Irvin, 1982).

Owens (1960) points out that siblings may resent parents' preoccupation with learning to care for their new babies and may express their wish for increased maternal attention by clinging to mothers' skirts and crying when their mothers are out of sight. Owens also states that if parents avoid dealing with guilt and denial in connection with having a premature infant, they may project their feelings on to an older child in a scapegoating process, labelling the child's distress-signalling behaviour as that of a "spoiled" child. Sensing this, the child may increase attempts to receive denied emotional attention, setting in motion a self-defeating cycle of interaction with her/his parents.

Siblings may be psychologically affected by a baby's premature birth even before he or she comes home. Some children may have resented the impending additions to the family and may develop guilt feelings if they come to believe that their resentment toward the fetuses caused them to be born prematurely (Roberts, 1977). Like other children who have a hospitalized sibling, the sisters and brothers of VLBW premature babies may become angry at the disruption in their lives caused by the illness of these infants. They may also fantasize that they caused the babies' illnesses and may upset themselves imagining ordeals the babies may be enduring in hospital (Hymovich and Chamberlin, 1980).

Not only is it stressful for an older child to realize she or he is no longer the sole object of parental attention (Aguilera and Messick, 1974) but the whole family system is changed by the new baby's arrival. For instance, living space may need to be reorganized and family relationships are altered to accommodate the arrival of a new member (Trause and Irvin, 1982).

Few parents are cognitively aware of all these ramifications. They are, however, fully aware that their older children's newly emerging negative behaviours are depleting their own already taxed physical and emotional resources.

The role of support systems.

Introduction Caplan (1964) was an early proponent of the importance of supportive intervention from intimates, professionals and community sources for people experiencing stressful life events. He proposed that those who most strongly influence a person under great stress are those who meet that person's need for love and personal interaction, as well as the need for authority and dependence. The former helping figures would be intimate partners, family members and friends, while professional caregivers and informal community caregivers, would fall into the latter category. Caplan's choice of terminology in describing the latter category is unfortunate. While all people are dependent on one another as members of the same society, not all have a need for authority if that means having others make all their decisions for them. Highly stressed people may occasionally regress to this state but more often view authority figures such as professionals, as sources of information and guidance that will provide a basis for their own decision making.

Fathers as providers of support Of all the sources of support for mothers of VLBW premature infants, existing research overwhelmingly shows that fathers are the most important. Kaplan and Mason (1960) see fathers' behaviour affecting how mothers react to events around prematurity while Mason (in Kennell and Klaus, 1982) expresses the belief that strong support from fathers helps mothers become attached to their premature babies, a view shared by Blake et al. (1975) and Jeffcoate et al. (1979).

In her study of mothers' performance of the tasks associated with dealing with their premature motherhood, Silcock (1984) found that one of the factors facilitating mothers' resumption of relating to their babies after dealing with their feelings of failure and grief, was their spouses' display of equal interest in the babies as manifested in regular visits to the NICU.

Only two studies have concentrated on examining the effect of fathers' supportiveness on the performance of their maternal role by mothers of VLBW premature infants. Crnic, Greenberg, Ragozin, Robinson and Basham (1983) found that fathers' support of mothers had several positive effects. It predicted mothers' attitudes to parenting and to maternal behaviour. This in turn may have positively influenced mothers' behaviour toward their infants since it was found that mothers with greater marital support had infants who were more responsive and more satisfying interactive partners. As well, mothers with high stress and high spousal support reported much higher life satisfaction than mothers with high life stress and low support from their partners.

A longitudinal study by Herzog (1979) reveals the unhappy consequences of fathers withholding support from their wives and some of the personal dynamics that underlie this behaviour. Among 200 families, Herzog found that 20% of parents had problems attaching to and parenting their premature babies, many of them VLBW premature infants. Reasons included on the one hand, mothers' affective state, mainly overt anger and depression, whose origins Herzog found difficult to pinpoint.

The other set of reasons related to two types of behaviour frequently exhibited by the fathers. The first type of behaviour emerged during pregnancy and centred around old and reactivated conflicts concerning the fathers' own needs for nurturing compared with the demands made on them to be nurturers, as well as their limited progenitors' role of fertilization compared to their wives' larger role of grower of human life. Many of these fathers manifested their conflicts in competitive behaviour intended to show they could be better parents than their wives.

The second type of behaviour exhibited by a different set of fathers, was withdrawal, and unfortunately Herzog (1979) does not discuss the dynamics behind this type of behaviour. Both types of behaviour had the same result for wives, however, since they deprived them of spousal support both during the puerperal period and for at least the succeeding 2 years.

Parenting disorders appeared in these families in the first year, including overt neglect and abuse of their babies. Interviews with the mothers revealed most of them felt deprived and lacking the resources to care for their babies. Herzog (1979) postulates that the main role of fathers may be to provide nurturing for mothers so that they can then nurture their babies; he suggests that mothers may need to be mothered themselves before they can perform that role for their children.

Unfortunately, Herzog (1979) does not supply background information on the parents in his study since it would have been informative, in the light of findings by Silcock (1984), to know whether the problem couples were experiencing other stresses or minimal support from other sources that may have contributed to their unsatisfactory parenting. Of the 14 women whom Silcock found coped well as mothers of VLBW premature infants, 7 had no support from their husbands. Perhaps they overcame this disadvantage became their middle- and upper-middle class backgrounds may have given them access to other sources of support which in turn may have made them feel more competent and less isolated.

There is accumulating evidence that sources of support other than spouses can be potent in assisting mothers of VLBW premature infants. In their study, Crnic, Greenberg, Ragozin, Robinson and Basham (1983) found that community support was as important as marital support in facilitating mothers' social/emotional growth. They further found that friendship was equally strong a predictor of mothers' parenting attitudes as marital support, with community support approaching significance.

Parent to parent support Parent to parent sharing has been found to be a valued source of support by parents of VLBW premature infants. This has occurred both informally and formally within the hospital setting. Six new premature mothers who shared a ward with a mother who had previously had a premature baby, all found their interchanges with her to be helpful (Lissenden, 1984). A number of couples visiting their babies in the NICU had a similarly rewarding experience. These parents had no one in their family and social circles with whom they could talk about their current parental stresses but found informal discussion with other parents in the NICU to be so helpful that they timed their visits to coincide with those of the parents they had come to know (Silcock, 1984).

Parental sharing in formal hospital-organized parent support groups has come to be recognized as a further form of support for parents of VLBW premature infants and groups now exist in several countries including Canada, the United States and Australia (Barnard, 1980b; Lissenden, 1984; Shosenberg, 1980b).

Parents told Kennell and Klaus (1982) that they felt great relief at being able to meet with other parents to express and compare feelings and feel supported. Similar views were contained in questionnaire responses from parents who had attended groups organized by Duhamel et al. (1974). Both Shosenberg (1980b) and Barnard (in Kennell and Klaus, 1982, p.186) stress the importance of the presence in these groups of selected "veteran" parents who have themselves had VLBW premature infants and to whom members parents can therefore relate particularly well. Professionals like nurses, social workers, paediatricians and paediatric psychologists may also be present to answer parents' questions (Duhamel et al., 1974; Shosenberg, 1980b).

There appears to be only one published study which evaluates the effects on parents of participation in a hospital-based support group. This study involved parents of VLBW premature infants of lower socioeconomic status and those who attended group meetings showed enhanced relationships with their babies compared with parents in a control group. Participating parents visited their babies more often, and touched, talked to and looked at their babies more en face during their visits. Three months after their babies' discharge, these parents felt more competent than the control parents (Minde et al., 1980).

Based on her experience with parents, Barnard (in Kennell and Klaus, 1982, p.186) recommends that the most important times for parents to receive parent group support are soon after their babies' births, secondly, when they are ready to take their babies home, and again when their babies are 5-6 months old. Yet Lissenden (1984) reports that while most parents in the study approved of the idea of parent support groups, few attended before 10 weeks postpartum and even fewer attended after their babies' discharge. Duhamel et al. (1974) also found that very few parents continued to attend parent group meetings after their babies came home. It may well be that both sets of parents found themselves so fully extended coping with their new babies, other children and commitments of various kinds, that they did not feel they had the energy to attend meetings. Some of them may also have found alternate sources of information and support. Or, as Shosenberg (1980b) points out, groups may not be for everyone, especially those families she encountered who had multiple stresses that needed the attention of several professionals.

Community support for parents There is very little research regarding bases of support for parents outside hospital walls. With regard to childcare services, Yu et al. (1981) found that only 1 of 17 families they studied had problems finding people to care for their other children while they themselves visited their VLBW premature infants in the NICU.

When support services are available and parents use them, both they and their babies benefit. In a longitudinal study of the availability of and utilization by parents of support resources, Phillip (1984) found that the ability of parents to use such resources during the perinatal period was positively correlated with subsequent parental acceptance of their babies. She further found that parents' ability to use support sources after their babies' discharge was even more highly related to parental acceptance of their babies.

Summary Certain propositions of Caplan (1964) concerning outcomes when support is given to or withheld from highly stressed persons, appear to have been confirmed by some of the studies just described. The foregoing discussion of the behaviour of fathers and siblings appears to confirm Caplan's statement that a set of complicated cultural, social and psychological factors determine how empathic family members will be with one who is in a highly stressful situation, in this case, mothers of VLBW premature infants. The data in the studies discussed also confirm Caplan's belief that not only the mental health of the sufferer but of others close to her, may be affected.

Caplan (1964) further states that current environmental conditions, together with attempts at support from various sources, interact with the internal mental and emotional state of a highly stressed person to produce an outcome that will either promote psychological health or be psychologically detrimental. This may explain the differences in maternal attachment shown by the seven mothers in Lissenden's study (1984) who coped successfully with the stresses of having VLBW premature babies without spousal support, compared to the 40 mothers in Herzog's study (1979) who were also without spousal support but displayed disordered parenting behaviour.

Summary

It is clear from the research that has been presented, that having and rearing VLBW premature infants is extremely stressful for many parents. Whether they experience it as a crisis as defined by theorists, is not as clear, bearing in mind that some theorists, like Caplan (1964), define a crisis not as an event but as the emotional and mental states with which some react to an event or set of events. For instance, Aguilera and Messick (1974) propose that a premature mother at home with her baby, feeling tired, seeing herself as a failure for having had a premature baby and lacking in confidence, all the while refraining from communicating her feelings to her husband, was not in crisis. To the authors, she only entered the crisis state after criticism from her visiting mother-in-law upset her so much that she cried uncontrollably and was unable to care for her baby. Her condition in turn so affected her husband that his work performance suffered enough for him to seek professional counselling.

If only such extreme behaviour is considered as symptomatic of people in crisis, then many of the parents who have been studied were not in that state. On the other hand, their experiences of having to live with the possibility of their infants' deaths, not just during the first few days but perhaps longer, aroused many of the feelings previously described by theorists as typical of the crisis reaction. The view of Taplin (1971) that some experience an event as a crisis if it violates preexisting expectations, is helpful in examining whether the behaviour of parents of VLBW premature infants is that of people in crisis. Having been socialized to expect that parenthood means giving birth to healthy fullterm infants, delivering a VLBW premature baby can come as a shocking violation of their expectations.

The proposition by Caplan (1964) and Halpern (1973) that people in crisis are particularly open to receive outside help, has mixed support from the research on parents of VLBW premature babies. Some parents practiced denial as a way of coping, others felt there were problem areas in their lives needing their attention more than dealing with problems presented by having a special baby. Lissenden (1984) states that parents' approach to such problems is influenced by their individual personalities and past and present life experiences. Other researchers have included the effect of other stresses induced by environmental factors, as well as the positive efforts at support parents receive from various quarters. The unique combination of all these factors for each parent will decide whether or not having a VLBW premature infant is a crisis for each mother and father.

For those who do develop crisis behaviour, it may be seen in gradations of mild to severe as Bloom (1963) has suggested. For instance, for some parents, their babies' illnesses may not be as severe or as long-lasting as in the case of other infants. Yet depending on the many interacting factors in the life of each parent, some with less ill infants may react with more severe crisis behaviour than some with more seriously ill infants.

The propositions of theorists regarding the precipitants and nature of the crisis state are well worth further study for the role they can play in facilitating the development of the most effective ways of helping parents deal with the many vicissitudes they experience. However, there are two missing dimensions in crisis theory at present. The first dimension relates to the fact that having a VLBW premature infant constitutes not just one major stressful event but a series of such events, each of which may reactivate crisis behaviour which had begun to run its course following a preceding stressful event. The second missing dimension concerns parents' own perceptions as to whether they are experiencing the events associated with parenting a VLBW premature infant as manageable or as taxing them beyond the limits of their present personal resources.

CHAPTER III

Methodology

This chapter deals with the methods of the study and the design and procedures employed in executing the research. The phenomenological paradigm is described. The use of the interview technique and the rationale for joint spousal interviews are discussed, and the interview procedures and process are described. Capsule profiles of each family are provided. The method of information analysis is outlined and the limitations of the study are presented.

The Phenomenological Approach in Psychological Research

The Origins and Nature of the Phenomenological Approach

The phenomenological approach is a research paradigm that has developed in this century in response to the shortcomings of the prevailing empiricist approach, also referred to as the natural science or positivist approach. In the opinion of phenomenologists, empiricist research methodology and its philosophical underpinnings are inadequate for the study of human behaviour because they have their roots in three flawed assumptions about the nature of human existence which were formulated by Descartes in the 17th century.

The first proposition states that there are two worlds rather than one; there is the subjective inner world of the person and there is the objective, concrete world which is external to the person and exists in separation from her or him. This has come to be known as the person/world split. For Descartes, only the objective world is worthy of investigation since it can be studied with the techniques of the natural scientist, whereas the subjective world is not nearly as amenable to such investigation and is therefore an unreliable source of knowledge (Barrett, 1979).

Descartes' second proposition states that just as the material world can be viewed and studied as a gigantic complex mechanism, so too, human beings should be seen as mechanisms of corresponding intricacy whose functioning should be investigated with the same techniques as those used to study the concrete world. Reacting against the low level of intellectual thought in his day, Descartes advocated the use of mathematical methods for the analysis of human behaviour (van den Berg, 1972).

The third proposition of Descartes refers to his view of the nature of human experiencing. He sees persons as consisting of two separate components: a physical body and secondly, a spirit/mind, each functioning independently of the other. This concept has since come to be known as the body/mind split. Descartes further affirmed its nature by proposing that each component be studied separately by different disciplines (Kockelmans, 1967).

The influence of Descartes' three propositions is clearly visible in the empiricist research approach. The person/world split is expressed in the empiricist view of human behaviour as mainly that of organisms reacting in predictable ways to stimuli in their environments; the notion conveyed is that of a world unilaterally impacting on an individual as an object without reciprocal acting by the individual on her or his world (Valle & King, 1978). The concept of persons as organisms is a reflection of the mechanistic view of human beings. It is exemplified in empiricists' insistence that the only human behaviours worthy and capable of scientific study are those that are observable, can be broken down for examination at a micro level, are measurable, quantifiable and can be replicated under controlled laboratory conditions (Giorgi, 1970; McConville, 1978). In empiricist research, the mind/body duality is manifested for example, in the conduct of experimental studies when researchers habitually limit participants to intellectual responses, excluding such other human responses as those of a physical or aesthetic nature (Spignesi, 1981).

Phenomenologists are critical of several components of the empiricist approach. They see the emphasis on studying only observable behaviour as providing an inadequate understanding of human experience since it precludes investigation of the subjective aspects of human existence (Giorgi, 1970; Keen, 1978). Furthermore, they assert that empiricist research methodologies as well as the stress on developing generalized statements about enduring patterns of human behaviour, ignore the many different contexts of and personal variations in, human experience (Colaizzi, 1978; Guba, 1979; Romanyshyn, 1978).

Phenomenologists see the observation and classification of lived human experience as the fundamental and primary phase of psychological enquiry, with measurement, experiment and theory being of only secondary importance (Romanyshyn, 1978; Van Kaam, 1966). From this belief flow a number of other assumptions relating to the nature of human existence and its exploration. These assumptions reveal the phenomenologists' total disagreement with Descartes' three propositions.

A major assumption underlying phenomenological enquiry states that we conduct our daily lives in the lifeworld, which is not a world external to us but the world of our individual lived experience and consequently the fundamental ground of our existence (Giorgi, 1970). The concept of the lifeworld is inextricably intertwined with that of consciousness, since, "there is no world without a consciousness to perceive it and, similarly, no consciousness without a world to be conscious of" (Valle & King, 1978, p. 12). Rather than seeing people as separate from their worlds, phenomenologists see them as indissolubly linked in mutual interaction; person and world are said to co-constitute each other (Kockelmans, 1967; Prescott & Valle, 1978). It is through conscious perceptual experience that we interface with our worlds and in the process invest our experiences with meaning

(McConville, 1978). We conduct this daily dialogue with our worlds not as entities composed of separate, independently functioning constituents, but as a whole composed of interacting physical, emotional, mental and spiritual components, a "body-subject-in-situation" (Prescott & Valle, 1978, p.159). The study of human experience must therefore be conducted from a holistic perspective.

The Purposes of Phenomenological Research

Psychologists employing the phenomenological research approach have in the past agreed that the general purpose of phenomenological enquiry is to extend and deepen knowledge concerning the nature of human experience as manifested in concrete, lived situations (Valle & King, 1978). However, several practitioners have recently begun to suggest further purposes for phenomenological research which extend beyond the goal of understanding.

Van Manen (1984) sees the aim of phenomenological research as that of studying what it means to be as fully human as possible. For him, this involves not only the investigation of peoples' actual experience, but also developing an understanding of the impediments that prevent them from living as richly as they potentially could. Research reports should not only contain descriptions of life experiences but also directly address issues relating to the enhancement of human existence.

Polakow (1984, pp.30,32) goes further than van Manen in suggesting that phenomenological researchers assume an advocacy role. To her, they are "interpretive critics" whose work is intended to be a "... call to action" in recommending both philosophical and practical strategies for improving the human condition. Her stance is supported by Werner (1983) who states that "responsible social research does make a political and moral commitment to the improvement of quality of life" (p.220).

Because this writer believes that research should be an instrument for personal and social change, the present study was conducted in the spirit and intent of the activist orientation outlined by the three practitioners just referred to.

Phenomenological Methodology

Phenomenologists have not only pointed out inadequacies in empiricist methodology, but have developed alternative methodologies. These are qualitative and descriptive rather than quantitative and analytical (McConville, 1978) and their foundation is that of naturalistic inquiry, that is, enquiry with people in their natural, everyday settings (Willems & Rauch, 1969) rather than the contrived experimental environments preferred by empiricists.

There are also differences between the two approaches with regard to the role of theory in the research enterprise. Phenomenologists view the empiricist emphasis on theory directed research as preventing investigators from getting close to the phenomena they wish to study. They are aware, however, that in their own research, there is a form of tentative theory implicit in their very choice of the dimensions of experience they choose to explore, as well as in the aspects of these dimensions they decide to emphasize. But this shadow theory is only a flexible guide, open to changes dictated by newly emerging elements in the research situation and by investigators' developing insights (Blankenburg, 1980).

Having recorded and reflected on participants' accounts of their experiences and having considered the contexts in which they occurred, phenomenologists endeavour to explicate the meanings the experiences held for the experiencers (Giorgi, 1970). The ultimate goal of phenomenological enquiry is to uncover the structure of the phenomenon under study; the structure is also referred to as the essence of the phenomenon (Merleau Ponty, 1962). These terms refer to the basic, unchanging nature of the phenomenon, no matter how idiosyncratically it may be experienced by individuals. Since structure or essence is only revealed through meaning, it is the task of the phenomenologist to discover that meaning (Valle & King, 1978). For this writer and others (van Manen, 1984), the term "essence" more truly connotes the basic, unchanging nature of a phenomenon and will therefore be used in preference to the term "structure".

Having uncovered the essences of phenomena through their interpretations of recounted experiences, phenomenologists then seek to ascertain their interpretations' applicability to other peoples' experiencing of the same phenomena. This enterprise differs from the empiricist ideal of achieving generalizability of findings to wider populations which, though seldom achieved (Kerlinger, 1973), is considered to be a desirable outcome of empiricist research. In the phenomenological approach, generalizability is replaced by intersubjectivity. This refers to the belief that each psychological phenomenon is a possible universal human experience, consequently descriptions of peoples' experiencing of phenomena, expressed in everyday language, have a universal appeal (Polakow, 1984; van Manen, 1984). This characteristic is not only the result of common species membership but typically occurs when phenomenological descriptions evoke a sense of recognition in individuals who have had very similar experiences. They then recount the description to others who in turn retell it to their personal circle. In this way, increasing numbers of people make the revealed meaning of the phenomenon a part of their own experience (Kockelmans, 1967; Polakow, 1984).

Methodological Techniques of Phenomenologists

For phenomenologists, the empiricist stress on researchers as objective observers of the behaviour they study, results in the dehumanization of those whose experiences they are examining, since it designates them as objects of study. In the phenomenological approach, those who have offered their experiences for investigation, are referred to as respondents or participants and they are considered to be co-investigators engaged in dialogue with researchers (Silvers, 1982). The behaviour of each impacts on the other and both are emotionally affected by what occurs in the course of the research enterprise (Silvers, 1982).

In addition to their emotional states, phenomenological researchers are required to be aware of other personal factors that might affect their perceptions during the research process. They attempt to bring to awareness their prejudices, philosophical preferences and prior preconceptions and then consciously set them aside so as to maintain a state of open-mindedness throughout their investigations. This act of conscious discovery of and suspension of biases, is referred to as bracketing (Deegan, 1981; Giorgi, 1970). It is unlikely that a researcher will ever be able to discover and suspend all his/her own prejudices, but an approximation to the ideal can be achieved.

Once having obtained participants' information, its examination and interpretation is conducted by firstly reading through individuals' statements and obtaining a sense of each person's total response to the main question of the study. Significant statements, referred to as meaning units, are then extracted for each participant and those showing common themes are grouped together and labelled. Their essential meanings are then presented by researchers in some concrete form (Levy, 1981; van Manen, 1984). The total process requires sustained, disciplined reflection as well as the sensitivity and creative capacity to discern the meanings underlying the spoken word (Colaizzi, 1978; Reinharz, 1983).

A variety of techniques are employed by phenomenologists to explore human experience and uncover the basic essences of psychological phenomena. The techniques most commonly used for receiving, recording and presenting interpretive accounts of lived experience are naturalistic observation, case studies, written protocols and interviews (Colaizzi, 1978; Guba, 1979; van Manen, 1984).

The interview. To phenomenologists, an interview is a social situation in which interviewer and interviewee converse with a purpose (Guba, 1979), which is, "to capture the respondents' lived experience outside the interview" (Mehan & Wood, 1975, p.51).

The interview as a research tool has several advantages for the phenomenologist. The interview context approximates that of everyday discourse since colloquial speech is employed on both sides and interviewees are free to move back and forth in time as they recount their experiences. A further advantage for interviewers is that they are in immediate personal contact with interviewees and so receive immediate responses from them with a consequent increased likelihood of their authenticity (Guba, 1979).

While both phenomenologists and empiricists agree that memory plays a vital role in accessing information for interviews, phenomenologists view the alleged unreliability and selectivity of memory differently from their empiricist counterparts. The phenomenological viewpoint states that we only remember when we have a motive for remembering and that the past as it appears now to us, is the past which is the most significant for us (van den Berg, 1972). Dealing with the contents of what we choose to remember, Keen (1978) states that experiences are meaningful when they are relevant and that relevance relates to something remembered or anticipated for remembering. Because faulty memory is part of our reality and often influences how we act in the future, it is part of our lived experience and therefore a legitimate area of study (van den Berg, 1972).

Summary

The phenomenological research approach is well suited for the exploration of parents' experience of having VLBW premature infants not only because of its concentration on lived experience, but also because of its assumption that all human behaviour is context related. This is particularly important in light of the limitations of the empiricist research studies reviewed in Chapter II. Several of the authors concede that a combination of personal and environmental factors contribute to the individual responses of each parent to their distinctive parenthood (Caplan et al., 1965; Duhamel et al., 1974;

Lissenden, 1984; Shosenberg, 1980b; Silcock, 1984). Yet no empiricist researcher has attempted to elicit from parents directly, their accounts of the ways in which they experienced the interplay of the many elements in their lives.

Similarly, those engaged in refining crisis theory as it applies to parents of premature infants, have to date failed to be specific in their approach to parents for their personal perceptions of firstly, the severity of the stress in each new harrowing situation they lived through, secondly, the extent to which they felt able to deal with these individual situations, and thirdly, the forms of support they found to be the most helpful.

The phenomenological approach was therefore chosen not only for the reasons described in Chapter I, but also to obtain parental information in the two areas just delineated. Furthermore, the present study, as a phenomenological study, was viewed not so much as supplementing empirical findings (Giorgi, 1970), but as expanding both the conception of the area of study and the methodology for investigating it. These purposes are embedded in the research design and research procedures whose description follows.

Research Design

The Interview Technique

The interview is often used by phenomenological researchers. Sociologists have developed three types of interview technique, the most structured being the schedule standardized interview whose wording and order of questions, listed on a preprinted sheet, are identical for all interviewees. The second type of interview, the nonstandardized interview, is the antithesis of the first type. No schedule of questions is used, no specific questions are prescribed, nor are questions asked in the same order with each interviewee; the ability and intuition of the interviewer are the determinants of success (Denzin, 1970).

The third type of interview is the nonschedule standardized interview which fits in a middle ground between types 1 and 2 (Denzin, 1970). It most closely approximates what has come to be known as the focussed interview (Merton & Kendall, 1946, p.541-542). In this type of interview, although interviewers seek the same information from each interviewee, they do not enforce a predetermined order of questioning. They use a list of questions as a guide but rephrase them to fit the characteristics of each person they interview (Denzin, 1970).

Because the focussed interview combines structure and flexibility and takes into account the uniqueness of each interviewee, it was the technique chosen for this study. The interview guide developed was based partly on existing research findings and partly on the writer's own research goals. The questions were roughly grouped to cover the period from conception through the months after the babies' homecoming. The content of the questions concerned the physical, emotional and mental aspects of parents' experience as well as the external stressors that impinged on them.

Additional questions covered two areas not directly addressed in the literature on parents of VLBW premature infants. The first area concerned parents' relationships with their own parents, since this has been shown to affect attitudes to parenthood (Smith, 1983) as well as their emotional responses to, and treatment of their infants (Fraiberg, 1980). The second area related to parents' individual philosophies of life and view of the future, since these are the guideposts which orient our perceptions of our current life experiences. It was surmised that information in these two areas could help to explain individual differences in parental behaviour. An outline of the interview guide is presented in Appendix 1.

Research Procedure

Participants in the Study

Volunteer couples were used as participants in the study since it was assumed that they would only be willing to donate their time and effort to a project that was meaningful to them.

Because the existing pool of parents who have had VLBW premature babies is small, extensive efforts over a period of 6 months were necessary before five couples were located who were willing to participate in the study. As a first step, several recommended obstetricians were contacted by letter and were sent copies of an explanatory letter and stamped envelopes for forwarding to possible volunteer couples. A follow-up telephone call was then made to obstetricians 14 days after mailing material to them. These efforts proved unsuccessful, mainly because so few of them had delivered babies in the required weight range. One of them suggested a couple who had already been recommended by a contact person in a childbirth organization. This couple agreed to participate.

Attempts to find couples through advertisements in the newsletter of a childbirth association and a provincial women's organization, also yielded negative results, as did written and telephoned requests to a caesarean mothers' group.

Other medical professionals were approached. Letters were sent to the neonatologists in the two tertiary hospitals in the city, enclosing the same material as had been sent to obstetricians. Follow-up telephone calls were then made. A meeting was held with one neonatologist when the nature and purposes of the study were discussed and suggestions offered to the writer for contacting couples known to the NICU staff. The approach made to the second neonatologist proved even more fruitful, since two couples contacted by him agreed to become part of the study.

Finally, a written request to the medical director of the city's high risk infant follow-up clinic, followed by telephone calls and personal meetings, proved successful and two of the couples contacted by the medical director expressed their willingness to participate in the study.

A sample letter to medical professionals is presented in Appendix 2 and the sample letter to parents constitutes Appendix 3.

In order to qualify for inclusion in the study, couples had to meet several criteria. Firstly, they had to be living in a stable relationship, whether cohabiting or married. This condition was intended to ensure as far as possible that the study would not be hampered by a couple terminating their involvement because of the breakup of their relationship.

A second requirement was that babies would have weighed 1,500 grams (approximately 3.3 lb) or less at birth. This is the standard definition of a VLBW premature infant employed by professionals. It was further required that babies had been home for at least 1 month. This was considered important for two reasons. The first reason related to the writer's interest in ascertaining whether volunteer parents' experiences would confirm research findings that the initial post-discharge period is an extremely difficult one for both parents and infants. It was felt that it would be most fruitful to begin exploring this area only after parents had had at least several weeks' experience with their babies at home and so would be likely to have relevant thoughts and feelings to relate. A second reason for requiring babies' minimum one-month domicile, relates to the writer's intent to use parents' initial information about the post-discharge weeks as a base from which to explore in subsequent interviews the evolution of parents' experiences over the succeeding months.

In order to ensure as far as possible couples' continued participation in the study, a further criterion of parents' suitability was that they intended to keep their babies. This information was requested confidentially in the letters to medical professionals to minimize the risk of losing a couple's participation because of the emotional upheaval they would experience in deciding to relinquish their baby.

A second assurance confidentially requested from medical professionals was that the infants of volunteer parents appeared likely to survive infancy. This information was requested firstly, to ensure as far as possible that equivalent information concerning the same phases of parents' experience would be available for all couples. Secondly, it was conjectured that those parents whose infants were very ill might find it too physically and emotionally taxing to cope with both that situation and the demands of in-depth interviews for the study.

Because of the difficulty in finding volunteer couples, it was found necessary in one case, to set aside the requirement that couples reside within city limits. This condition had been included to provide a commonality of urban-based experiences as opposed to some of the difficulties uniquely experienced by parents living geographically distant from their hospitalized babies. The requirement was also desirable for the convenience of the writer who had to rely on public transportation for travelling to and from couples' homes. The couple in question lived in a town bordering on city limits and the mother worked in the city where the father also fulfilled periodic work assignments as a self-employed artisan. The driving time from their home to the city centre was no more than that required by commuters living on the fringes of the city, and some of their leisure time was spent in the city.

All the couples in the study were Canadian born and Caucasian and all of them were married. The mothers' ages ranged from 23-33 years with the average age being 29 years. The fathers were aged 26-32 years, with an average age of 31 years. In the case of two of the couples, their VLBW premature infant was their only child. Of the three remaining couples, one couple had two older children while the remaining two couples each had one older child. The five couples were representative of the general population according to the Index of Social Class Position developed by Hollingshead and Redlich (1958). The five classes in the Index range from Class I, the uppermost social level, to Class V, the lowest social level. Of the five couples in this study, one qualified for Class II rating, three for Class III rating and one for

Class IV rating. A summary of the demographic data relating to the five couples is contained in Appendix 4.

Although the five couples met several common criteria, they differed in their personal and family backgrounds. The following capsule profiles of each couple and their children are intended to convey an indication of the uniqueness of each parent and each family. The profiles appear in the order in which the couples were first interviewed.

Beth and Philip Beth was 33 years old and before starting her family, she had been an educator of exceptional children. Philip, aged 32 years, was a purchasing manager in a large corporation. They had been married 11 years. Their two older children were John, aged 5 years, and Stephen, aged 2 years. They were both fullterm babies, born at home by normal delivery.

Both Beth and Philip had wanted children and they read and attended classes to prepare for the home births of John and Stephen. Initially, Beth was ambivalent about having a third child, feeling already extended in caring for two small children. However, she developed a close relationship with Martin, the fetus, while awaiting his birth in hospital, and with Martin the baby after he was born.

Martin was born at 24 weeks gestation and weighed 700 grams (1 lb 8 oz), which was appropriate for his gestational age. His was a normal delivery. At the time of the first interview with his parents, Martin had been home for 5 weeks. His chronological age was 13 months and his age adjusted for prematurity was 9 months. He had spent a year in the NICU.

Janet and Will Janet, aged 32 years, was a secretary and Will, a plumber and steamfitter, was 31 years old. They had been married 4½ years. They had both received treatment for infertility in the year prior to Denise's conception since they both wished to have children.

Janet was forced to cut short her maternity leave and return to work 7 months after giving birth to Denise, or face losing her position to retrenchment. Will lost his employment concurrently with Janet's return to work and at the time of the last interview, he was still a fulltime homemaker.

Denise was their first child and was delivered by caesarean section at 29 weeks gestation. Her birthweight of 1,391 grams (3 lb 1 oz) was appropriate for her gestational age. At the time of the first interview with her parents, Denise had been home for 2½ months. Her chronological age was then 4½ months and her age adjusted for prematurity was 7 weeks.

Barb and Noel Barb was 26 years old and a bookkeeper/ homemaker. Noel, a self-employed sheet metal mechanic, was 32 years old. They had been married 5 years and had always intended to have children.

Annette, their only child, was born by normal delivery at 27 weeks gestation and weighed 930 grams (2 lb 1 oz). This birthweight was appropriate for her gestational age. At the time of the first interview with her parents, Annette's chronological age was 15 months and her age adjusted for prematurity was 12 months. She had been home for 12½ months.

Barb had worked both as a waitress and bookkeeper prior to Annette's birth but was able to spend her full year's maternity leave at home with her. She then resumed work as a bookkeeper in a parttime capacity. Noel had lost his fulltime employment because of the economic recession and subsequently founded his own business.

Pam and Kevin Pam was a fulltime homemaker, aged 28 years, while Kevin, aged 30 years, was a compositor on a newspaper. They had been married 7 years and had a daughter, Jill, aged 3 years. She was a fullterm baby and had been a normal delivery. She was 2 years old at the time Corey was conceived. Both were wanted children and Pam had had infertility treatments to facilitate each pregnancy.

Corey was born at 28 weeks gestation and weighed 1,022 grams (2 lb 4 oz). This birthweight was appropriate for his gestational age. At the time of the first interview with his parents, Corey's chronological age was 6½ months and his age adjusted for prematurity was 3½ months. He had been home for nearly 4 months.

During the period of the study, Pam applied for training as a registered nursing assistant and studied for, wrote and passed a required examination.

Sharon and Jim Sharon was a fulltime homemaker and was 23 years old. Jim was 26 years old and worked as an automotive partsperson. They had been married 5 years and had intended to have several children. Seth, aged 4 years, was delivered by caesarean section at 38 weeks gestation because he was pressing against Sharon's only kidney, severely impairing its ability to function.

Melissa was delivered by caesarean section at 29 weeks gestation with a birthweight of 1,021 grams (2 lb 4 oz). This birthweight was appropriate for her gestational age. At the time of the first interview with her parents, Melissa had been home for 13 months. Her chronological age was 15½ months and her age adjusted for prematurity was 12½ months.

The Interviews: Procedures and Process

Preface. This section is written in the first person to convey as truly as possible the flavour of the personal nature of the interview process as it actually occurred. The practice of writing in the first person is advocated in phenomenological research not only to render accounts as vivid as possible, but to convey that all experience is potentially common experience and therefore to be shared (van Manen, 1984).

The first interview. After couples had mailed to me a completed form indicating their willingness to be part of the study, I telephoned them to introduce myself, to acknowledge receipt of the form and to arrange the day and time of our first meeting. During this call to the first couple I interviewed, I stated that the purpose of the first meeting was for us to meet face to face, for them to put any questions they had about the study, and on the basis of this meeting, to decide if they still wished to participate; I would then telephone them a few days later to learn of their decisions. However, it was clear early in my first interview with this couple, that they were not willing to spend it as I had outlined on the telephone, for they began to talk about their experiences as soon as I had seated myself.

When I telephoned the second couple for interview, I again outlined my proposed procedure for my first visit. When I arrived at their home, they too immediately began to talk of their experiences. They also stated that the fact that they had sent a signed form offering to participate, meant that they wanted to start talking about their experiences in the first interview. I therefore also commenced interviewing the three remaining couples in the first meeting, after preliminary discussion as to what they foresaw happening in the interview sessions.

Couples had received a 2-page letter explaining the goals and nature of the study when first contacted about participating in it. At the beginning of the first interview, I asked each person if they had any questions about the content of the letter or the study in general. Three couples indicated they understood the purpose of the study. One mother was under the impression the study was intended to focus on the babies' progress since birth while one couple stated with seemingly embarrassed laughter, that they had read the letter a long time ago, had misplaced it, and could not remember its contents. I gave them a further copy of the letter.

In all cases, I spent some time in the initial interview inviting questions and briefly outlining my reasons for doing the study and describing how I would proceed. I offered personal information, stating that I was working toward a master's degree in psychology and had a particular interest in supporting parents in their difficult job of child-rearing and secondly, in helping babies and their families to develop loving relationships. I further stated that although I had never been married nor had children of my own, I had had 20 years of volunteer involvement with children of various ages, and having at times acted as a surrogate parent, knew first-hand how demanding parenthood can be. To amplify this personal picture for readers, I add the following information. I am a woman aged 55 years with professional experience as a secretary, administrator, group facilitator and counsellor, and intend to work in the areas of infant-parent relationships and parenting education.

Each couple was interviewed three times, the meetings extending over a period of 4-5 months at generally 6-week intervals. Each meeting lasted approximately 2 hours, although actual interview time varied from 45 to 90 minutes. At the beginning of the first interview, each partner was given an Informed Consent Form to read and sign (see Appendix 5). At the end of the second interview, each couple was given an Information Sheet and requested to provide basic information that would contribute to a demographic picture of the 10 participants (see Appendix 6).

During our first meeting, I informed couples that I would type up the content of our interview and on a separate sheet, summarize the main points they had made. I would then mail copies to them to read and for us to discuss during our second meeting. I stated my purposes for doing this were to help me be aware of occasions when I had misheard or misinterpreted what they had said, as well as to receive from them any further thoughts that might have come to them while reading the summary. I further stated that I would welcome their perceptions of the first interview as they would help me to conduct the remaining two interviews with them as effectively as possible.

This interim consultation was a modified form of that suggested by Colaizzi (1978, pp.61-62) which he terms a "validating step" in the interpretive process. It proved practically helpful in the case of two mothers. One mother indicated an area of important information which I had misunderstood and our ensuing discussion provided fresh insights into the way she and perhaps other mothers dealt with their anticipatory grief. In the case of another mother, the summary appeared to serve as a means of not only providing self-validation, but also justifying her need for assistance from trained nurses in the daily care of her sick son. She stated that she had shown the summary to the nurses working with him at the time to acquaint them with the history of her son's illness and the number and seriousness of the stressful events she and her husband had lived through.

Three parents chose to retain their copies of the summaries and I found the summarizing exercise helpful as a rehearsal for the final identification of significant statements and the subsequent pondering on their meanings.

Location of interviews. In my letter inviting parents to participate in the study, I had offered to interview them either in their homes or at the university. All expressed a preference for being interviewed in their homes and this arrangement appeared to me to have several advantages. It seemed likely that parents might feel comfortable with me sooner if they were my hosts rather than be in the reverse situation, and that they might also feel more free to talk about painful events in familiar surroundings. From a personal standpoint, I felt the study would be more meaningful to me if I could meet the babies whose special circumstances of birth had led to my meetings with their parents and around whom much of our discussion would revolve. In addition, I surmised that my personal witnessing of parents' experiences would not only provide lived affirmation of their verbal reports, but might also supply additional details about such areas as their babies' current status, their relationship with her or him, sex roles, family relationships and family lifestyles.

In several instances, I saw confirmation of parents' accounts. Two couples did indeed look as tired as they said they felt and the babies' episodes of fussing appeared to be as frequent as their parents had reported. In the course of a visit with another couple, I observed examples of their admitted ineffective disciplining of their toddler as well as of the traditional sex role patterns they had previously talked about. And in the case of a fourth couple, I saw first-hand the physical and emotional demands being made on them to care for two toddlers as well as their sick premature son who still required three sets of technical equipment in his bedroom to direct air into his lungs and remove secretions from them.

While all three interviews were conducted in the homes of the four city-based couples, this was not the case with the out-of-town couple. The first two meetings took place in an office at the university since I was unable to reach their home by public transportation, and was unable to arrange private transport for the particular days and times. I was anxious to meet them and their baby at home at least once for the reasons previously stated, as well as considering it important that there be as much commonality as possible in the conditions under which I interviewed couples in order that each couple might have an equal choice of the optimal conditions for participating in the interviews. The last interview was held in the couple's home and they were more relaxed and spoke more freely on that occasion than on the previous two occasions. Their increased ease may have been due to their gradually feeling more comfortable with me and with the interview situation; of all the couples, they were the most nervous, particularly during the first meeting. However, my expressed wish to meet their baby and their more accustomed roles of hosts in their own home, may well have contributed to their notably greater ease during the third interview.

It became clear from the time of the first interview, that families wished me to enter to some extent into their lives. On my arrival, parents and I chatted while I removed my outdoor clothing. They then brought me their babies whom I held and/or talked to. This first step seemed to enable parents to see me as approachable and it also put me at my ease. One couple showed me over the main floor of their home and on a second occasion, the father showed me the excellent garden furniture he had made. A second couple invited me on two separate occasions to visit their sick son in his bedroom and be part of the ritual of seeing his brothers to bed in the same room. These two boys always met me at the door on my arrival, and would show me a favourite toy or invite me to view television with them. In another home, the baby's sister took me on a tour of the house and garden while in a third home, the baby's older brother enjoyed recording his voice on my tape recorder and then hearing it played back.

Some interviews were interrupted by telephone calls, unexpected visitors and parents' need to attend to their babies' requirements and those of their other children. In the case of one couple, their baby was present for all three interviews and was so active in exercising her vocal cords during the last one, that portions of the recording of her parents' words were inaudible.

Parents were generous with both their time and hospitality. I was unfailingly offered refreshments and two fathers drove me to convenient bus stops when they learned that I travelled by public transport. One of the fathers stated that he would like a copy of the full thesis instead of the summary I had promised in the Letter of Consent. This document had stated that the full thesis would be available in a specific named library at the university. The father stated he had access to photocopying facilities and would make copies for each of the other couples. His offer was received with varying degrees of enthusiasm, partly because some couples found difficulty understanding the nature of a thesis even after receiving repeated explanations. However, one mother stated she would keep the thesis on a shelf to commemorate for herself and her husband all they had been through.

Interviewing couples together. Several reasons contributed to the decision to interview couples together. One reason pertained to the fact that the birth and nurturing of a baby is a joint experience and therefore it is fitting that the retelling of the total experience should be a joint parental enterprise. A related reason concerned the possibility that one spouse might be more willing to recount painful events if she or he knew the other would be present to offer support as well as sharing in the narration of those events.

There is little discussion in the sociological literature regarding the pros and cons of interviewing spouses together or separately. Huston and Robins (1982) see as a major advantage of joint interviews, the fact that spouses' mutual contributions tend to help to reduce the occurrence of what is termed response reactivity. This refers to a tendency in some interviewees to portray themselves in the best possible light. The authors assert that spouses' practice of correcting and supplementing each others' narrations, tends to limit response reactivity to minimum levels.

According to Allan (1980), spousal interaction during interviews can have other positive effects. In the dual recall of an incident, couples tend to produce a final, single account through a process of negotiation with possible occasional mediation from the interviewer, and in the course of this dynamic, the different realities experienced by each partner are revealed. A further advantage of joint interviews is the possibility that topics may surface during spousal discussion which would not have come to light in individual interviews.

Allan (1980) also sees joint interviews at least partially meeting the empiricist criticism that interviewees' memories are subject to distortion. He notes that when spouses together relate an incident, they often modify each other's accounts to correct unacknowledged biases and distortions. An example of distortion, idealization, is corrected in this way when, for instance, one spouse presents an idealized picture of his or her family of origin and the other spouse introduces reality-based information to balance the picture or even challenges the unrealistic portrayal.

The various checks and balances spouses provide during interviews are likely to provide more valid accounts of events than individual interviews might. Joint interviews also may prove rewarding for couples as they enjoy hearing each other's reminiscences and supply missing details in each other's narratives. On the other hand, if theirs is not a harmonious relationship, this will be revealed by the manner in which they interact during the interview, thus providing the interviewer with additional elements to incorporate in the picture of their lives she or he is attempting to develop.

On the negative side, it is possible that one partner may refrain from making statements of value to the study for fear of hurting or antagonizing the other. A further possibility is that one spouse may persuade the other prior to an interview, to withhold certain information in the belief that it should be "kept in the family" and not revealed to strangers, whereas the willing spouse may have imparted the information if she or he had been interviewed alone.

It is not clear to me whether the fact that the couples in this study were interviewed together, prevented individual partners from expressing themselves as freely as they wished. One favourable indicator is the fact that in the case of all five couples, there was at least one occasion during an interview, when one partner expressed anger or resentment toward the other, although in two cases, this was conveyed in a low-key manner.

The interviewer's responsibilities. In the course of the interviews, some parents requested advice concerning problems they were currently having with their babies as well as general information concerning the normal progress of premature babies. I offered what information I could in response to requests and supplied to interested couples the name of a current book written especially for parents by two developmental psychologists on the many aspects of parenting premature infants. One couple mentioned their dilemma at having to decide whether or not to agree to their baby having a particular operation without possessing information on which to base their decision. I was able to obtain for them a journal article containing the most recent research findings in the area concerned. I not only offered this assistance out of the belief that it is part of a researcher's ethic to do so, but because I was moved by the parents' expression of need for reassurance and by their obvious wish to make the best possible decisions concerning their babies' welfare.

Throughout the interviews, I attempted to be conscious of my own inner processes and of those occasions when they began to interfere with my effectiveness as a researcher. One such instance occurred when I first heard a mother criticizing her treatment in hospital by medical professionals. Her account triggered memories of experiences I had had when hospitalized on certain occasions, and the memories were accompanied by feelings of anger. It was necessary for me to make deliberate efforts to bracket those thoughts and feelings to enable me to hear without distortion and to frame my subsequent questions in objective language.

Analysis of Interview Content

The content of interviews was intensively perused and interpretations rendered of the essential meanings for parents of their experiences. Common themes emerging from the totality of parental accounts were identified.

Several steps were involved in the foregoing process. The tape-recorded interviews were transcribed verbatim and attached to each protocol, as were my notes made after each visit to record impressions as well as events and verbal exchanges that had occurred outside the recorded sessions.

In the next step, I read each protocol several times, firstly to reacquaint myself with its contents and secondly, to discern significant statements. To locate these statements, the dual approaches suggested by van Manen (1984) were employed. In the line-by-line approach, each sentence was read to discover what it revealed about the experience being described. The second approach, the highlighting approach, involved the identification and underlining of statements and phrases that conveyed the quintessential nature of the experiences being described. The material gathered by these two approaches was then considered as a whole and where appropriate, combined into meaning units. Continuous reflection then yielded the essences of the spouses' experiences as emerging from the content of the meaning units. These meanings were then compared across couples and major themes common to all couples then emerged into the researcher's awareness.

During this interpretive process, I attempted to be conscious of and then to bracket, all predisposing beliefs and biases, including previous research findings. It was while engaged in unfolding major themes, that I brought existing research findings to awareness to be used only as confirmatory guideposts or as challenges for further reflection. I bore in mind that my interpretations were only examples of possible meanings and that other interpretations were equally possible and valid.

Limitations of the Study

The most severe limitation of this study relates to the fact that there were no couples from the groups who most often give birth to VLBW premature babies, that is, the most socially disadvantaged segment of the society's population. It would have been valuable to have at least one couple from this most important group for more than representational purposes only. None of the existing studies has directly compared these couples' experiences with the experiencing of more advantaged parents. Moreover, those studies that have included disadvantaged parents, have not attempted to highlight them in any way, so that their special problems and needs as parents of VLBW premature infants still remain virtually unexplored.

The second limitation concerns the fact that 2 of the 5 couples were interviewed a year after their babies' arrival home, while the other three couples' babies had been home for much shorter periods, ranging from 5 weeks to 3 months. It was noteworthy that the 2 couples whose babies had been home the longest, were also those whose statements were the least elaborated and whose interviews were the shortest in length. These characteristics may have been due in part to the personalities of the 4 parents concerned and to their apparent lack of experience in maintaining prolonged dialogue and sustained reflection. The 2 mothers in particular, were less verbally expressive than the other 3 mothers, and provided far less information about the post-discharge period than did the other mothers. One can only speculate as to the role that the passing of time and intervening events played in lessening the impact of the immediate post-discharge months on the perceptions of the 2 sets of parents with the older infants. The fact that 1 of these infants had the shortest and least troubled adaptation period of all 5 babies, after arriving home, may well have diminished the importance of that phase for her parents.

CHAPTER IV

Parents' Experiences: The Main Themes

This chapter reveals the five main themes that emerged from parental accounts of their experiences. Each theme unfolds through parent's own words. A deeper understanding of parents' experiences is sought by means of the researcher's attempts to uncover the meanings underlying parents' statements and their non-verbal behaviours during interviews such as types of laughter. Quotations from the research literature are intended to illustrate the widespread nature of some experiences and to illuminate others as yet little explored.

Theme 1: Pregnancy, Delivery and the Early Postpartal Period- More Trauma Than Joy

Introduction

During this period, each parent had to deal with a number of stressful situations. Although some were unique to individuals and to couples, there were also some common to all. These related to concern about the health of mothers, of the fetuses and later, of the newborn infants.

Pregnancy and Delivery

Couples' histories. None of the mothers had a trouble-free pregnancy. Their problems varied according to the type and gravity of the complications experienced by each of them. Pam's pregnancy was the most continuously troubled and had the most marked psychological effects.

Pam and Kevin Pam had experienced problems with the functioning of her fallopian tubes after using an IUD. As a result, she was obliged to take fertility pills to facilitate both her pregnancies with Jill and with Corey. Following Jill's birth, she had three miscarriages. As soon as she was certain of her pregnancy with Corey, she began taking a synthetic hormone at her doctor's suggestion, to facilitate the production of progesterone and so support the pregnancy. To further decrease the likelihood of another miscarriage, her doctor also recommended that she spend the first 5 months of pregnancy in bed, a practice she found difficult to maintain. Even with these measures, however, her doctor had warned that he would probably have to deliver her baby prematurely by caesarean section.

During her pregnancy, Pam suffered from two major health problems. The first was extreme nausea which she assumed was the cause of the continuing and alarming weakness she experienced.

> Oh I was really sick with nausea all the time. I thought I was dying.

Pam's second health problem involved episodes of bleeding. The first episode occurred during the first week of her pregnancy and thereafter she lived in constant fear of miscarrying.

> I always thought when I stood up that I was going to lose him.

Excessive bleeding occurred 3 months into her pregnancy and again after another 3-month interval. The final episode occurred in the 28th week of her pregnancy. On this occasion, Pam was alone at home and became so frightened by the heavy bleeding that she requested her brother-in-law who lived nearby, to drive her to the hospital. She was in the intensive care unit for 2 days and after a further 5 days, she went into prolonged and painful labour.

> It was a bad labour compared with Jill's. It started about 5 but by midnight it got really bad and it lasted till about 6 before I had a caesarean because I was hemorrhaging.

Kevin was with Pam during her labour and was concerned that all her suffering might end in only another miscarriage.

> I was only worried about Pam - all this pain - I was hoping ... it wouldn't end up like the others.

While recuperating in hospital, Pam became aware of emotions aroused by recent events which she had suppressed and which finally seemed to be demanding expression.

> There were some days that were pretty bad. I started taking tranquillizers and stuff like that. I thought I was going to lose control ... I thought I was going to explode there for a while. I tried to pull myself together.

One factor contributing to Pam's extreme distress at this time related to her taking a laxative prescribed by an intern at her request some hours before labour commenced. Only after she had taken the medication, did the nurse on duty inform her that it might stimulate uterine contractions. This statement after the fact angered Pam, as well as evoking feelings of guilt that her action may have precipitated Corey's premature birth.

Pam was in hospital for a week after Corey's birth. Apart from bleeding for 1 month postpartum and contracting a bladder infection, she experienced no postpartal complications. Several months after her return home, she was informed that the precipitating cause of the bleeding and Corey's consequent premature delivery, had been placenta previa, a condition involving the placenta's movement out of its normal position resulting in blockage of the baby's exit path from the uterus (Verny, 1981).

Pam's history of miscarriages appears to be a common phenomenon among mothers of very low birthweight (VLBW) premature infants. Of the 60 mothers studied by Minde et al. (1980), 50% had lost 1-7 babies during previous pregnancies. These parents were of lower socioeconomic status, therefore environmental factors as well as physical problems, may have accounted for the high number of miscarriages the mothers suffered.

Janet and Will Like Pam, Janet had had treatment for an infertility problem partly caused by blocked fallopian tubes. Also like Pam, she had experienced bleeding in the first trimester and consequently had to curtail her activities to avoid a miscarriage. However, she was able to continue in fulltime employment.

Her health was good during her second trimester but one morning in the 29th week of her pregnancy, she discovered that a continuous stream of colourless liquid was flowing from her vagina.

> I knew something was the matter but it didn't register that my water had broken because I didn't know what that was ... So we went to the hospital ... The worst thing for me was during the drive ... not knowing what was happening.

Janet's feelings of suspense have been shared by other primigravidas who experienced leakage of amniotic fluid before giving birth to premature infants. After being advised by her doctor to continue her normal daily activities, one such mother spent 2 weeks in a state of fear and confusion while the fluid flowed from her body (Lissenden, 1984).

Janet was in the intensive care unit for 4 days. The drug she was given to halt the contractions that had commenced, made her hot and dry-mouthed. Because the contractions had still not ceased by the fourth day, doctors decided to perform a caesarean section to deliver Denise. Janet understood their reasons to be that Denise was lying in the breech position in the uterus and her neck could be broken during the course of a vaginal delivery.

Although Janet welcomed the surgery as a release from her pain and discomfort, she also feared she and Denise might not survive it.

> I think the worst part of it was at first not knowing whether your baby is going to make it and then I was concerned whether I was going to live ... There was a point when I said to Will, "Well, I'm afraid I'm not going to make it."

Will chose to ignore Janet's fears, treating them lightheartedly.

Janet: I think he laughed.

Will: I knew she'd make it .... (laughs). She always makes a mountain out of a molehill. I mean, if there had been any complications, the doctor would certainly have told me.

Janet's relief at the prospect of an end to her pain, counterbalanced by fear for the lives of her baby and herself, have been found to be common maternal reactions to an impending caesarean delivery (Affonso & Stichler, 1980).

Janet returned home 10 days after Denise's birth. She experienced postpartal bleeding for 12 weeks and at one point required emergency treatment for it. When she questioned her doctor regarding the reasons for Denise's premature birth, he stated that she had chosen to be born early. This explanation, although incomplete, is in accord with the reality that no precipitating cause can be found for many premature births.

Sharon and Jim Sharon was the third of the three mothers who delivered their babies by caesarean section. Her physical anomalies of one kidney and two uteruses had caused problems during her pregnancy with Seth, necessitating his delivery by caesarean section at 38 weeks gestation. She therefore expected to deliver Melissa by the same method.

Her pregnancy proceeded normally until the 27th week when she spent a week in hospital for treatment of a bladder and kidney infection. Two weeks later, she experienced intense pain different in nature to that precipitating her earlier admission to hospital. On the instructions of the obstetrician, Jim drove her to the hospital and within a half-hour of her arrival, doctors decided to perform a caesarean section because of the erratic functioning of Melissa's heart.

Jim anticipated Melissa's impending surgical delivery with apprehension but was reassured by staff reports on her postnatal condition.

> I knew for sure before we even went to the hospital that they'd take the baby ... I felt it was going to be a daughter anyways, and I said, "Oh, you're going to take my daughter away." And I was worried about that but once I seen the doctor and asked how is she and he said, "Fine". Then I talked to the nurses and they said, "Well, she's breathing on her own."

After Melissa's birth, Sharon recovered well, was discharged after 6 days and suffered no postoperative problems. The reasons for Melissa's prematurity were not clearly presented to Sharon.

> I don't know exactly what happened but they said it was fetal distress, but my neighbour does ultrasounds and she told me I had an abruptio, that's why. Something to do with the placenta. So Melissa wasn't getting any food or oxygen and that's why she was so small too.

Sharon appears to have been referring to the condition known as abruptio placenta, in which a normally situated placenta becomes detached from the uterus, depriving the fetus of the means of maintaining life (Stedman, 1982).

The three mothers who had caesarean deliveries found it an unsatisfying experience for different reasons.

> Sharon: 'Cause I knew I was going to have a C-section again, I was going to plan to have an epidermal (sic) ... to stay awake so I could see it, so you could hold your baby right away as soon as they're born. So that (being anaesthetized) really upset me.
>
> Pam: You don't get to see them when they first go to sleep and wake up. It's not the same thing.

Like Sharon and Pam, other women have felt robbed of the first joyful moments with their babies because of anesthesia. Mothers interviewed by Affonso and Stichler (1980) during the first days following their caesarean deliveries, expressed dissatisfaction at having missed the immediate rewards of normal delivery.

Janet's reaction was more complex, responding to both Denise's prematurity and her surgical delivery.

> It even bothers me now. There's times I'd go up there (to the hospital) ... I couldn't associate her with me. I'm wondering if mothers who have babies by caesarean feel that because I don't even know anyone who has had a caesarean. That sort of emptiness where you go and look at that baby and say, "Make sure that some day you're going to be big because you're my baby."

Janet was not alone in at first feeling unrelated to her baby. The same phenomenon has been noted in other mothers who were not conscious during their infants' deliveries (Curtis-Jenkins in Blake et al., 1975, p. 283).

Beth and Philip Beth was the fourth mother to experience a bleeding problem, the most prolonged and serious of them all. Her ordeal began in the 18th week of her pregnancy when bleeding commenced. It developed into hemorrhaging a week later and she was confined to bed at home. This did not slow the hemorrhaging nor end the extreme fatigue she was experiencing and the situation distressed Philip for several reasons.

> I was worried. Beth was losing an awful lot of blood ... and all of the things we were doing didn't seem to be helping the situation. From the practical point of view, my immediate reaction was how we were going to continue as a family.

Because her week in bed at home had not improved her condition, Beth was hospitalized and attempted to view her situation positively.

> At that point, I was saying, "If it was not meant to be, I'll feel OK about that. Whatever is trying to be shown to me here, I'm trying to go with." That was our whole philosophy.

After a week in hospital, Beth returned home, worried about the family situation, but she had to return to hospital within a few days when the hemorrhaging continued, and her doctor warned her that it could eventually cause her death.

The obstetrician finally ordered blood transfusions for Beth, but her relief turned to terror after the first transfusion. She reacted negatively to a component in the blood with such symptoms as shaking and hallucinations. Her symptoms were misinterpreted by the staff who gave her a second transfusion with the same frightening results. During the time Beth was suffering these reactions, Philip was convinced that she would not survive them. His fears about her condition were compounded by the difficulties he encountered in trying to contact the obstetrician to obtain information from him and to get him to visit Beth.

Beth and Philip had been warned by the obstetrician that most babies born at 25 weeks gestation or less rarely survive, and that they should therefore not expect Martin to live after his delivery. As a result, Beth felt the odd one out among the other expectant mothers on the ward.

> The other women, they'd say, "What're you in for?"
> And I'd say, "I'm waiting for this baby to die."

Beth went into labour in her 25th week of pregnancy and 15 hours after her second blood transfusion. She was in labour for 24 hours with Philip and a midwife friend by her side. When she gave birth, neither the obstetrician nor the intern was present, and Martin was delivered by the staff midwife who happened to be visiting the ward at the time. The birth was a positive experience for both Beth and Philip as they trusted the midwife and the staff left them in complete privacy in the delivery room.

Because Martin was born in a secondary hospital with only limited facilities to treat newborns, he was transported to a tertiary hospital 3 hours after delivery and Beth was able to accompany him. Beth was discharged from hospital 5 days postpartum and her recovery was normal. She was not informed as to the possible physiological factors that may have precipitated Martin's premature birth.

Over a year after Martin's birth, Philip still felt angry with the obstetrician who, without first consulting with the hospital neonatologist, had warned Beth and himself that their baby would not survive delivery because of low gestational age.

> It's a case of someone being too big for his britches ... the way it was laid out to me... I had written Martin off when Beth started going into labour. No hope at all ... When we were in this emotional state it was very difficult for me ... to believe that there was another route and that Martin was going to live.

Barb and Noel Barb's pregnancy and delivery were not as traumatic as those of the other four mothers. However, from the moment she first learned she was pregnant, she lived in constant fear that she might be plagued by physical problems as her sister had been, and that, like her sister, she might have a baby who was not normal. The two fears seemed to be linked in her mind.

> I was really scared throughout my whole pregnancy because my sister had troubles with her pregnancies. I was really paranoid that something would be wrong, like happened to my sister.
>
> Inv: You mean there was something wrong with your sister's baby?
>
> Barb: Ya, she has Down's syndrome ... I don't know, at the back of my mind it was always there. I don't know what I'd do if something like that happened to me.

Barb's pregnancy was normal until the 27th week when she began hemorrhaging one night and was admitted to two hospitals before finally being transported to a tertiary hospital. Noel was unprepared for this unusual sequence of events which he found extremely distressing.

> Oh God, I was kind of shocked. I thought she might be having a miscarriage. We went to the (local) hospital ... They didn't have no facilities for anything like that ... then we had to go to Edmonton. The whole process was a big runaround from one hospital to another and another, three in one night.

Barb received a blood transfusion on arrival in the intensive care unit of the tertiary hospital but she continued to hemorrhage for 4 days. She then gave birth to Annette by vaginal delivery and was discharged 3 days later. She experienced no physical postpartal problems. Barb's doctor informed her that her hemorrhaging and Annette's subsequent premature birth had been caused by the condition of abruptio placenta.

The suddenness of premature birth. Even to those parents who had had warning signals that their pregnancies were not proceeding normally, the swift course of events culminating in their babies' premature births unnerved them.

> Sharon: I was really scared 'cause all of a sudden they said, "Well, we're going to take her by C-section." I thought, "Oh, no" 'cause I was only 29 weeks ... I'd never even heard of premature babies before. I didn't even know there was that intensive care there, what all they could do for her.
>
> Noel: Oh God, I was kind of shocked ... We never even went to prenatal classes ... so all of a sudden you're a father 3 months before your time.

Will experienced contradictory feelings about Denise's unexpected arrival.

> I just felt nature takes its course and I just couldn't understand it ... You just don't expect it to happen to you.

Awaiting their babies' births - fathers in the waiting room. Philip was the only father to be with his wife when she delivered their baby. The other four fathers each waited alone in a hospital waiting room, each in a different frame of mind but with tension predominating in all of them.

> Noel: I came up to the hospital to visit her and she was already in the delivery room and I thought, "Here we go, she's going to have a baby" and the way the doctors were talking there was not much chance of the baby living.
>
> Kevin: I was ... in the waiting room. It was really hard ... she was just 6 months pregnant. I was really worried, more about the baby ... I thought she (Pam) would be OK; the doctor seemed to be fairly confident.
>
> Jim: I was really scared ... I was worried for both of them ... I was really nervous ... because you don't know what's happening. You're not there so you can't see what's going on. And I'd seen Sharon was having real problems at that time so I had reasons to be afraid.
>
> Will: It was just after midnight and I'm sitting in the TV room by myself wondering how I'm going to react. When I heard wheels roll, I went outside and the doctor said, ... "You've got a little girl." It was such a shock. The doctor had told us it sounded like a boy. I was expecting a little boy for the longest time. So I went back into the waiting room to get my act together ... to convince myself it wasn't a boy and to enjoy it.

The Early Postpartal Period

Parents' first sight of their babies. Parents' emotional reactions ranged from disbelief to pleased surprise when they saw their newborns for the first time.

Janet experienced a painful and confused dichotomy of feelings, hoping on the one hand that the baby was not hers because her hold on life was so tenuous, and on the other hand, fearing that the baby might not be hers, that she had not become a mother after all.

> The first time I looked at her, I just prayed to God there was a mistake and she really wasn't my baby because ... I don't know, I just didn't think she was mine you know, and I think that was the hardest part ... I mean everybody, the doctor said she was doing well and I was thinking, "How can they be saying that she's doing well when she's hooked up to all those things and things are buzzing and everyone's running around ..." I don't know, I think I was really just afraid she was not mine.

Will's reaction was in complete contrast and of an apparently more optimistic nature.

> Even though she was so small, she was like a real baby. The thing about having her so small is you get a chance to see her grow from the start ... (she) was just a nice size.

Pam and Kevin shared similar first impressions.

> Pam: I thought he was awfully pitiful looking.
>
> Kevin: I was the same as Pam. I thought he looked really small and he was all wrinkly. He just seemed to be all skin and bones, there was no meat on him.

Barb stated that she "couldn't describe" how she felt when she first saw Annette while Noel's first emotion was fear for Annette's life.

> I was scared when I saw Annette. She was so small and full of tubes.

Beth was oblivious to Martin's physical appearance as she concentrated all her energies on willing him to live.

> I didn't even notice what he looked like ... I was so busy trying to connect with him ... whole emotions sitting inside me, all of it was channelled into saying, "Stay with me, please don't go."

Sharon and Philip were both amazed and delighted by the miniature perfection of their babies.

> Sharon: She was so tiny, it was hard to believe something so tiny ... had all their hands, their fingers, their toes, everything ... that something so tiny was living. It was unreal. It was a nice kind of experience, in a way.
>
> Philip: For me, it was amazing because ... I had envisioned seeing something far, far ... less humanlike ... Martin reacted exactly the same as the other two boys ... He had his eyes, ears, nose, mouth, fingers, and he was crying to beat the band, just as the other two boys did, but ... just a bit miniature.

Lissenden (1984) recounts a similar reaction from a father who saw the VLBW premature infants in the NICU as "small and perfect" (p.148).

Fathers' lives during mothers' illness at home and in hospital. During those periods when mothers were ill at home or hospitalized, most fathers became exhausted from the extra burden of responsibilities they were required to carry.

Will was unemployed at the time of Janet's admission to hospital but he was upset by the erratic nature of his daily life during her stay there. He found it particularly frustrating to have to interrupt his work on the furniture he was making for Denise's room.

> I was just doing what I could at home ... By the time I'd get started on Denise's dresser, I'd have to drop everything to go to the hospital and then I'd come home for another hour at the job and then go to some place for supper .... It was pretty hectic for me, I tell you.
>
> Janet: He didn't have time to think ... when he did come to the hospital, he'd be so emotional.

Kevin found it exhausting to work his usual night shift, visit Pam daily and coordinate Jill's care by his mother.

> I'd leave here in the afternoon to go visit Pam and then I'd go to work from there .... Mom was here off and on for about a week 'cause I'd have a day off and I'd bring Jill home and we'd be here and then take her back, or I'd bring mom here and take here back..So it was back and forth. It was tiring ... I never seemed to have time ... to just sit down and relax.
>
> Jim: That week I worked .... I [had] phoned her parents and dropped Seth off there. I spent most of my time down there [the hospital]. I was just here to sleep. I'd have supper here and then I'd go to visit Sharon. I ran around, for sure.

Of all the fathers, Phillip was required to assume extra responsibilities most often and for the longest periods of time, while continuing fulltime employment. During Beth's two separate weeks of hemorrhaging at home and during her two hospitalizations, she and

Philip were fortunate to have a neighbour willing to care for their two small sons during the day. Philip drove them to the neighbour's home in the morning and called for them on his way home from work. He also did the shopping, household tasks and caretaking of the children because Beth had been warned to move around as little as possible.

Philip's daily routine became even more arduous during Beth's 6-week stay in hospital.

> I would .... pick the boys up ... come back home, cook the meal and because Stephen was only one-and-a-half and John was only four-and-a-half, they had to get to bed relatively early. So we'd get fed and dishes cleaned up .... We'd run down and see Beth for 20 minutes and then drive home, put jammies [pyjamas] on, have a bath, then bed, and then it was time to clean house. We would be up quite early in the morning ... the kids were constantly tired. It was very difficult to get them out of bed and dressed ... Then into the car and off to the neighbour.

Other fathers have reported a similarly hectic way of life during their wives' stay in hospital. For example, 40 first-time fathers of premature babies participating in a study by Evans (1985) stated that they had little time to themselves during the first 2 postpartal weeks. Life was particularly stressful for several fathers interviewed by Benfield et al. (1976). These fathers had to spend hours driving long distances to visit their wives and babies.

Anticipatory grief. Unlike other parents in previous studies, those in the present study did not manifest anticipatory grief in terms of lack of visiting (Benfield et al., 1976) or in reluctance to establish physical contact with their babies (Minde et al., 1978). None of the parents remembered consciously feeling unwilling to love their babies in case they died, as did certain parents interviewed by Lissenden (1984). Parents rather appeared to deal with their anticipatory grief by concentrating on their hope that their babies would live. They did this through activities such as constant, protracted visits to the NICU, the provision of breast milk, and alertness to the smallest signs of improvement in their infants' health. Newman (1980) has described these positive parental activities as coping with commitment.

For two mothers, however, it was difficult to remain consistently hopeful. They expressed their anticipatory grief in a manner often found among mothers of premature infants, namely, postponement of practical preparations for their babies' homecomings (Cramer, 1982).

> Barb: I didn't have anything set up till I knew she was going to live.
>
> Sharon: Well, I did say at one time, "I don't really like those clothes in there in case she never does come home." I don't know ... I never did think she was going to die or anything ... I kind of always knew she'd be OK.

In his interviews with 30 mothers, Cramer (1982) found that none of them prepared a crib for their infants until it was clear that the babies' health was definitely improving.

Mothers' homecomings without their infants. Mothers found it painful to return home without their babies, expressing this from different points of view.

Beth, Pam and Sharon felt deprived of the joy they had earned through their physical and emotional suffering.

Beth:	I hated coming home without him.
Pam:	The day that you're leaving the hospital and going home with nothing .... I felt like this is the end of the world. I went through so much and I left with nothing. I thought I'd die that day .... I just felt desperate. He [Kevin] dropped me off at home .... People were phoning me and I couldn't even talk to people. I was just crying all day and I couldn't wait to get back up there the next day.
Sharon:	You go home without your baby so you felt robbed.

For Janet, the physical emptiness of Denise's room symbolized her own emotional emptiness, a feeling Barb also experienced at having to leave the hospital without the infant who had been part of her for so many weeks.

Janet:	The room was ready for her but there was no baby until October. That's what I found difficult.
Barb:	It was a very empty feeling. I felt just empty, that I had delivered a child but wasn't taking her home.

According to Kennell & Klaus (1982), a large percentage of mothers who have been separated from their premature babies have reported feeling empty, both while hospitalized and after going home. The authors see parallels between the physical emptiness of the uterus and the physical emptiness of the mother's arms with no baby to hold. It is possible that these experiences may in turn induce feelings of emotional emptiness in the affected mothers.

The husbands of the five mothers did not express equivalent distress at having to accompany their wives home without their babies. For instance, Will and Noel responded pragmatically to their wives' expressed unhappiness, stating that the babies were in the place where they could get the best help. Nevertheless, Will was able to appreciate that a mother's close biological connection with her baby would cause her particularly intense distress when they had to be separated.

> Well, it's like Janet has told me, like the baby has come from within her. It's a different kind of feeling than for me even though I am the father.

Summary

During the phases of pregnancy, delivery and the early postpartal period, fathers appeared to have had two roles: firstly, that of supportive partner and secondly, that of apprehensive observer. Not only did fathers have to expend energy on these two roles, but four of them also had to maintain their fulltime employment.

As supportive partners, fathers comforted their wives during the problems of pregnancy, visited them in hospital each day, and ensured their peace of mind by maintaining the functioning of the family home and where necessary, by organizing the care of the other children.

As worried observers of their wives' health problems, and later those of their infants, fathers repeatedly experienced the agony of not knowing, just as mothers did. Couples lived in constant suspense with regard to possible miscarriages, the likely consequences of mothers' hemorrhaging and the delivery and subsequent critical status of their newborn infants.

For mothers, the very condition of pregnancy as well as the physical complications each of them developed, combined to constitute an overwhelming experience in which they saw themselves as being at the mercy of their bodies (Blankenburg, 1980). They were powerless to prevent the bleeding, the flow of amniotic fluid, the placental aberrations occurring within their bodies and the impact of these on the fetuses they were carrying. It was as if they experienced their bodies as "the other", the enemy, (Moss, 1978, p. 91), rather than integral parts of their own selves.

In a different but equally real sense, parents were at the mercy of the professionals on whose judgment they had to rely for decisions affecting the survival of both mothers and infants. This situation continued during the babies' treatment in the NICU.

Theme 2: The Neonatal Intensive Care Unit (NICU) - Parents' Other World

Introduction

Parental visiting in NICU's was introduced over a decade ago (Blake et al., 1975). It is therefore surprising that only a very small amount of research has been directed to eliciting parents' accounts of their experiences in the NICU environment. This lack of research interest is difficult to understand when the particular nature of a NICU is considered. At first sight it appears to belong more to the world of science fiction than that of everyday reality, dominated as it is by sophisticated equipment of diverse types. There is a general atmosphere of fast-paced urgency as sick babies are rushed in from operating theatres and ambulances, and their individual problems are discussed by groups of doctors and nurses in terminology comprehensible only to themselves.

Some of the premature babies lie on small mattresses with heaters above them to maintain their body temperatures, and various items of life support apparatus are connected to their bodies. Most premature babies are assisted by similar types of equipment and many of them initially lie in incubators, which are small beds with plexiglas domes over them (Newman, 1980). Very low birthweight (VLBW) premature babies have tiny bodies which are semi-transparent with wrinkled skin of unusual color. In the early weeks of life, they lie almost motionless in constant sleep. The total impact of a room full of these babies has led one researcher to speculate that it resembles "a zoo with many strange creatures behind glass" (Dubois, 1975, p. 22).

To facilitate contact with the babies, the incubators have openings called ports (Bidder et al., 1974). Through these, staff and parents can insert their hands to attend to the babies' physical needs and to caress them as a way of conveying affection to them. These acts assist to some extent in dissolving "the incubator barrier" (Bidder et al., 1974, p. 766).

The parents in this study first saw their babies in the NICU anywhere from 1-10 hours postpartum. Not only were both parents still suffering from the tension of days and even weeks of worry about the mothers' health problems but they were still reeling from the shock of an unexpected birth. In addition, the mothers were suffering the effects of having so recently given birth. It is therefore not surprising that for many parents in this debilitated physical and emotional state, their first experience of the alien NICU environment was a traumatic one.

For Noel, the NICU was intimidating enough that he felt unable to return for a period.

> I was scared. I wouldn't go back for 2 weeks or so.

Sharon's reaction to the emergency atmosphere of the NICU was one of pervasive unease.

> The whole room, like all the machines and some of the babies and stuff ... made me feel nervous.

Lissenden (1984) received similar reports from some of the 33 Australian couples she interviewed. One father's first visit left him so devastated that his total being seemed to freeze as if to protect him from reexperiencing the effect the visit had had on him.

> I was shocked when I first went to the NICU and things left me numb. I just couldn't talk about it.

Among the mothers Lissenden (1984) talked to, emotional responses to their first experience of the NICU ranged from surprise and amazement to shock and fright.

Because their babies' stays in the NICU lasted 2-3 months and in one case for over a year, the parents in this study spent many hours visiting them first in the critical care nursery, and then in the convalescent nursery for babies soon to be discharged. As a result, they became more accustomed to the NICU but various aspects of its environment militated against their feeling completely at ease there.

The Physical Environment

Several components of the physical environment of the NICU stressed parents. Barb was upset by the overcrowded conditions in the critical care nursery she visited because they deprived her of an adequate amount of physical space in which to comfortably coexist with others.

> That place is really, really busy. When they had an admittance there were five or six doctors for every small baby. You couldn't even get around. It was awful. A lot of time [it was] really crowded.

The overcrowding may have been a factor additional to the high room temperature needed to maintain the body temperature of infants on open beds. To Will this meant that his desire to be alert while visiting his baby was frustrated by his body's reaction to the warmth of the room.

Janet: The hotness didn't bother me but it did Will. He couldn't stand it and he was falling asleep.

Will: Ya, I was.

Lissenden (1984) points out that in addition to the overcrowding and heat in the NICU, parents have to cope with the bright light and noise that are almost continuously present day and night.

The Mechanical Environment

Even more stressful to parents than physical factors, was the nature and amount of technological intervention their babies received and its effect on both the babies and themselves.

Parents reluctantly accepted that their babies' lives could only be saved with the assistance of sophisticated equipment.

Will: At the time she was hooked up to all the machines, you kinda figured maybe that's how it's got to be. Maybe if she's not hooked up, she's not going to stay there.

For both Janet and Pam, their baby's defencelessness against technological intrusion was a source of anguish.

Janet: I cried every time I went in there. Even after 2 months I still cried there ... I'd never seen a little baby like that. And just thinking like, why do they have to - I don't know - just the smallness and the tubes.

Pam: I felt so sorry for him, really pitiful looking, so peaceful and here we're interrupting him and sticking things in him and poking him. Definitely he wasn't at peace in the hospital. You could see a "leave me alone" sort of thing. I would often think, "What must he be thinking: 'Is this what I've come into the world for?'" Because it's so nice

> inside and he came out to all this pain. He was in so much pain.

One of the mothers interviewed by Lissenden and her colleagues (1984) expressed similar feelings of distress at her baby's vulnerability.

> He was all respirator and tubes. There was not much baby. I felt so sorry for him. It was a very upsetting time.

Even more harrowing for parents were those occasions when by chance they appeared on the scene while drastic procedures were being performed on their babies.

Barb was forced to watch helplessly for a prolonged period while desperate staff probed the most sensitive parts of Annette's body, inflicting constant pain on her.

> They were putting in the IV just as I walked in and they were breaking all her veins to put the IV in, couldn't get a vein. Took an hour to get an IV in.

Beth entered an even more serious situation in which her son was in danger of dying during a technical procedure.

> Martin just about died the last time he was extubated and he wasn't an easy child to reintubate again; they couldn't get it back down. I just happened to come along that same time and I saw Dr. .... and he was just shaking and he said, "We can't wait any longer." He was without oxygen for 10 minutes and they were really concerned that they had waited too long.

In addition to the emotional pain their infants' subjection to technical interventions often caused them, many parents felt intimidated by the equipment. Their resulting nervousness impeded their efforts to perform physical caretaking tasks for their babies, and to generally develop a close relationship with them.

> Janet: I couldn't change a diaper for a month. They'd say, "You do it" and every time I'd go to do it, she had the intravenous in different places and I was afraid I was going to hurt her.

> Beth: It wasn't that I didn't want to touch my baby. It's the wires and the feeling that I know he really doesn't want to be touched right now.

Parents feel apprehensive about various types of apparatus but it was the alarms sounded by cardiac and respiratory monitors that most upset them. The monitors, electrical devices located beside or above incubators, and connected to the babies, enable staff to keep track of infants' heart and breathing rates. Should their heartbeats slow down, a condition known as bradycardia, the monitors will sound, warning staff (Shosenberg, 1980a). These episodes of decelerated heartbeats are colloquially referred to as "brads."

Some NICU's also use thin pads placed under specific babies' mattresses. The pads are sensitive to breathing movements and their purpose is to alert staff should babies cease breathing, a condition known as apnea. Apnea monitors also sound if babies move off the pads or are picked up (Shosenberg, 1980a).

The sounding of the monitor alarms was particularly nerve-wracking to parents for two reasons. Not only did these alarms add to the general noise level but their very tone seemed to convey a message of danger and possible death.

> Pam: The noises were very weird, kind of spooky.

Janet: It's so noisy and ... babies are having brads and machines are going off. Every time a machine goes off you would think it was your baby and we used to jump literally, both of us.

Noel: There's monitors going off and that really bothers you. You look for a nurse ... something's wrong with the monitor or they stop breathing. When these monitors go off you expect the worst, what's happening now?

Kevin: Kind scary sometimes. There was always that thought: "Maybe it's Corey."

Barb: It's actually frightening.

Enriquez, Harrell and Putman (1980) reported similar fear-inducing effects of monitors on parents with whom they talked. Many of them were under the impression that the sounding of a monitor alarm meant a baby was dying.

In the only study which deals in detail with parents' reactions to the various types of monitors, Yu et al. (1981) obtained ambiguous information from the questionnaire responses of 20 Australian couples whose infants had been in the NICU for 10 days. The responses were assigned to one of three categories which the authors do not define. Twenty-eight percent of parents' reactions to the cardiac and respiratory monitors fell in the Concerned/Frightened category and the same percentage of responses fell in the Relieved/Reassured category. The remaining 44% of parental responses fell in the Unconcerned/ Indifferent category.

The apnea mattress monitors evoked similar reactions. Eighteen percent of parents were concerned or frightened by these monitors while 42% were relieved or reassured by their presence. A further 42% of parents appeared unconcerned or indifferent to them.

It is generally difficult to interpret these results because the categories have not been defined. It is particularly so when attempting to discern the meanings behind the responses in the Unconcerned/Indifferent category. They may in part refer to the fact that only half the infants had gestational ages under 32 weeks and that infants of higher gestational ages usually suffer from fewer physical problems than those of lower gestational ages. The heart and lung functioning of the babies of greater gestational ages would therefore be more likely to be stable than those of their gestationally younger peers, resulting in fewer physical malfunctions to trigger the monitor alarms. Even when they did sound, it is likely some parents would not be unduly upset because they had seen continuing evidence that their own babies were generally progressing well.

It is also understandable that as many as 42% of parents felt positively toward the apnea mattress monitor. Because apneic episodes involve cessation of breathing and so can quickly become life threatening, parents of the affected babies might well have viewed the alarms as their babies' life savers.

In a rare study examining parents' attitudes to NICU equipment in general, Harper et al. (1976) found that only 36% of parents felt positively about the equipment used on their babies. The authors comment on the irony of a situation in which a majority of parents feared a technology which medical professionals had expected would be reassuring to them.

The Human Environment

During their babies' hospitalizations, the most important people in the lives of parents were their babies and the professionals caring for them. Parents were therefore engaged in two sets of relationships, those with their infants and those with the professional staff. Because the latter relationships extended over a lengthy period of time and were of a complex nature, they will be discussed as a separate theme.

Enduring the trauma of their infants' illnesses. Because each of the five infants developed at least one serious health problem soon after birth, their parents' visits to them were conducted in an atmosphere of suspense.

Some parents' fear about their babies' possible deaths had arisen even before their initial visit to the NICU. The first alarm came for Philip and Beth an hour after Martin's birth, when he turned grey and became very still. They thought he had died until they learned that his heart was still beating.

Barb and Noel received little encouragement from doctors to hope that Annette might live. Barb was particularly hurt by her personal doctor's lack of interest in Annette.

> Nobody ever said [she would live]. My doctor wouldn't even look at her. Wouldn't even go see her. "I never saw the baby" she said, "only in the delivery room." Then a couple of days later I told her she was doing real good and she said, "Don't get your hopes up."

Similarly, Will had been warned by staff prior to his first visiting Denise, that her survival ~~was not assured.~~ Nevertheless, he was unprepared for the sight of his newborn daughter connected to the many life support mechanisms she needed at the time.

> I knew there was no guarantee, like they told me ... they had put her under sedation because she was fighting so hard to do everything on her own and they needed to keep her strength up just for staying alive. I never expected this, to be fighting so hard to make it, you know. You just had to hope for the best.

For all the parents, hope proved very difficult to sustain as their babies each experienced a pattern of progress alternating with setbacks. Annette developed breathing problems soon after delivery, necessitating her placement on a respirator for her first week of life. She progressed well enough to be taken off it for a week but she then had to be placed on it again for a day. Secretions accumulated in her lungs and bronchial tubes and she had to remain on oxygen for almost the entire remaining 8 weeks she spent in the NICU. Throughout this period she was also being treated for necrotizing enterocolitis, a condition involving cell deterioration in, and bleeding of her intestinal tract (Stedman, 1982). Her symptoms and extended treatment caused her parents to fear for her life.

> Noel: They had to take her off milk and put her on

> intravenous ... Kind of threw us into a scare. We were really worried.
>
> Barb: They start bleeding .... she did have it real bad.

Necrotizing enterocolitis was also diagnosed in Melissa 1 week after her birth and her treatment over several days included alternating milk feeds and intravenous feeding. When it became clear that her digestive system could not yet cope with milk, she was maintained on intravenous feeding for most of her two-month stay in the NICU. During this period, Sharon watched as a baby was rushed into the NICU for emergency treatment. The baby reminded her of Melissa and of the fact that her survival was not yet certain.

> I just couldn't handle it, it was just too soon. I thought, "Ya, that's how they could turn around."

Only after the first month did the staff begin to talk encouragingly to Jim and Sharon about a positive prognosis for Melissa.

When Denise developed an infection in the first few days of life, Will and Janet had to helplessly watch the NICU staff attempt various medical strategies to treat her problem.

> Janet: She had an infection of the bowel which was pretty serious because she couldn't feed on anything. They had to do a complete cleanout and start all over again and whatever they started her on then didn't work, so they had to take her off and start her on something else again.

Denise too needed intravenous feeding for most of her stay in the NICU. This was a source of worry to Janet, who, like many other parents (Lissenden, 1984), remained worried about her baby's survival until she saw she was able to receive and tolerate milk and was gaining weight.

For Kevin and Pam, worry deepened into anguish after Corey developed a serious lung condition in his second week of life. He became critically ill in the third week when both of his lungs collapsed, and one night Pam and Kevin wept together because they expected him to die at any time. Their fear for his life increased when they learned that laboratory tests had failed to reveal what specific infections were present in Corey's lungs, and consequently the doctors were unable to prescribe antibiotics to treat the problem. This uncertainty induced a sense of impotence that intensified the hopelessness Pam and Kevin were experiencing.

> Pam: "When he got bad, it [her flow of breast milk] just stopped. I tried .... and I'd be sitting there saying to myself, 'Why'm I doing this? It's pointless, he's not going to live'."
>
> Kevin: "You're standing around and he's getting worse and worse."

Even after Corey recovered from his most serious setback, the doctors still feared he might have another relapse. This fear was realized when his one lung again collapsed shortly after his crisis of the third week. As a result, Kevin and Pam continued to live with the expectation of another relapse up to the day of his discharge.

The ordeals experienced by Philip and Beth were the most frequent and long-lasting of all five couples. This was due to the fact that Martin spent a year in the NICU and during that time he had to undergo several surgical interventions. In his third week of life, Martin was diagnosed as suffering from bronchopulmonary dysplasia, a serious condition in which there is deterioration of lung tissue accompanied by lung collapse (Schraeder & Donar, 1983). When Martin's lungs showed signs of improving, three attempts were made to remove the ventilating tube which had been inserted in his nose and trachea to channel air into his lungs. All these attempts were unsuccessful and on one occasion, Martin nearly died. Surgery revealed that scar tissue had formed around the tube, preventing air from entering the trachea. During a subsequent operation, a tracheostomy was performed, in which a tube was inserted at the top of his breastbone so that air could pass through this tube, bypassing the scarred area below the nose and mouth.

Beth and Philip agreed to performance of the tracheostomy with a great deal of trepidation. They had been warned that it would delay Martin's speech development and necessitate the use of machines to perform his respiratory functions and to clear his lungs of secretions.

> Beth: I remember ... we had no idea ... when he [the neonatologist] mentioned a trach, it devastated us ... my God, that's a heavy intervention.

The unpredictability of the course of their babies' struggles, kept parents in a constant state of apprehension. This was exacerbated by their feelings of powerlessness to relieve their babies' suffering. All the parents had was hope, incrementally strengthened with each small sign of improvement displayed by their infants. McCarton (1986) sees this period of repeated ordeals relieved by small victories, as an emotional roller-coaster ride for parents, whose resultant emotional scarring can be viewed as constituting a "battered-parent syndrome" (p.6).

Becoming attached to their infants. While coping with the succession of physical hazards their babies encountered, the main source of gratification for parents was their slowly developing relationships with their infants.

Experiencing the fetus as a person Some mothers had begun to feel close to their infants during pregnancy, sensing them as living persons.

> Janet: When I used to go to bed, I talked to her. I'd just say, "How are you?" or sing to her.
>
> Barb: She always felt like a real person. She was always active.

During the weeks she was hospitalized and hemorrhaging continuously, Beth was torn between wanting to go home where she was needed, and staying in hospital to give Martin the fetus the maximum opportunity to develop to the stage most favourable for his birth and survival. This turmoil one day prompted her to reach out and communicate with him.

> I remember writing a letter to him saying, "Please tell me what you want. I've had it, I can't do it anymore."

Arbeit (1975) sees mothers' assigning of human characteristics to their fetuses as a way of initiating a definition of them as children. This seems to have been the case with Janet, Barb and Beth, but in Beth's case, her appeal to Martin the fetus moved their relationship into the realm of person-to-person dialogue.

Parents' first eye contact with their infants Parents had to wait much longer than parents of fullterm infants for their babies' eyes to open. Barb and Noel had the longest period of delay, having to wait 3 weeks before Annette opened her eyes fully for the first time.

The need to wait longer than usual for their first eye contact with their infants, did not appear to be a major source of frustration to parents because the NICU staff had explained to them that it was normal for such immature infants to sleep through their first postnatal days and even weeks.

> Barb: Well, when they're that tiny they sleep a lot anyway. So even when her eyes did open when you were there, she was asleep.

Parents did, however, quickly note any efforts of their infants to open their eyes

> Philip: His eyes were still fused together but he was trying to open them.

> Beth: He was really trying to see the light. I think he was really curious about what was going on.

Pam and Kevin became excited when they realized that Corey's eye opening signalled that he had recognized them.

> Pam: He'd open his eyes as soon as I'd get there and start talking to him. Just by our voices he could pick it up and we'd say, "Oh, he's staring at us, he knows that we're here."

Lissenden (1984) reports that infants in her study who were under 27 weeks' gestation, had their eyes closed for approximately the first week of life.

Parents' physical contact with their infants All the parents appreciated the opportunity to touch and stroke their infants within their incubators. Commencing with their first tactile contact with Corey on the day of his birth, Kevin and Pam found their physical contact with him particularly rewarding. During subsequent weeks, the nurses informed them that their touching and stroking were effecting improvement in Corey's health, as registered by heart and oxygen monitor readings and by the calming in his emotional state. This demonstration of the therapeutic effect of touch on premature infants has been confirmed by research findings which have shown that touching infants helps them to relax as well as facilitating improved breathing, weight gain and physical development (Kennell & Klaus, 1982).

However, for Noel, touching Annette in the NICU was a frustrating experience. He felt separated from her by the artificial conditions under which he was allowed to do so.

> I didn't feel close to her ... until she was actually home because for me when she's in an incubator and you get your hand in, you still have gloves on.

The first opportunity to hold their babies outside their incubators came to couples at varying times, due to the fact that this event was dependent on infants first attaining specific body weights. The occasion was of symbolic importance to parents, enabling them to confirm the reality of their babies' existence through the experiencing of their physical solidity, and affirming the parent-child connection through body-to-body contact. The experience was different for each parent, and not always rewarding.

> Kevin: It was...nice to hold him. I felt like you really had a baby when you could hold him and rock him.
>
> Pam: I held him once and he turned blue on me. I didn't hold him very much after that. [while Corey was in the NICU]
>
> Jim: I was scared. I figured she was so small, if I break her ...
>
> Sharon: I thought, "I'm finally holding my baby but it only feels like blankets."

Visiting their infants All five couples appeared to consider it important to maintain continuous contact with their infants. All the mothers visited the NICU daily with fathers varying from nightly visits as in Will's case, to approximately five times a week in the cases of Kevin, Philip and Jim. The frequency of Noel's visits depended on the demands of the work he contracted to do as this included travelling to other parts of the province.

Parents offer numerous reasons for visiting their VLBW premature babies. Reports by parents in Lissenden's study (1984) indicated that some felt impelled to visit their infants to reassure themselves visually that they did, in fact, have a child. Some of these parents believed their babies sensed they were their parents while other parents were not sure if this was the case. Yet other parents felt there was a mutual need for them and their babies to see one another and they felt sure their babies recognized them by voice and touch.

This appears to have been the case with Pam who talked directly to Corey.

> When he was sick, I would say, "What a good boy you are" and ... "Mummy loves you." I'd say that to him every day.

Several reasons combined to give Beth's daily visits to Martin a sense of urgency. Her concerns about him related not only to his medical problems but to her relationship with him.

> I couldn't let 2 days go by ... it would drive me nuts. I needed to keep something - ... When we felt we had conceived, there was a time when I didn't want Martin because I didn't know if I could give anymore. But I will spend the rest of my life ... not making it up to him, but trying to be very aware of him and as a mother, that's all I can do. I still have lots of guilt ... a lot of it has to do with my feelings ... because nurses would give me this pat story, "Oh yes, he knows you" and I'd say, "Listen, a relationship takes time." And I'd give him 2 hours because that was all I could give him ... If I was away from Martin, I felt that I had let him down.

Becoming their infants' fulltime parents No matter how often parents visit their babies, they are required to forfeit most of their parenting role to the NICU staff until their infants' physical condition has improved and stabilized. As a result, it can take parents a period of time to move beyond seeing their babies as "hospital property" (Perlman, 1986, p. 11).

NICU staff have become increasingly aware of parents' difficult situation and now encourage them to participate in performing caretaking tasks for their infants. In the case of the couples in this study, individual parents' experiences varied widely in their positive and negative connotations. Parents were initially instructed by nurses in the performance of the various tasks and at first this proved tension provoking for Sharon and Pam.

> Sharon: At first I wasn't very comfortable ... I like to do something on my own but if I know there's a nurse standing there ... they're kind of watching you and they write reports on you too and you know that .... So you get kind of nervous and uptight and then that's when something does go wrong.

Pam too felt uneasy knowing she was being observed. She felt as if her capability as a mother was being tested.

> I was watched a lot and they would take my hand and show me. You knew they were watching you. They'd take away the bottle to see how much he'd got, measure it, see when he fell asleep. A lot of times there was no way I could get him to drink. So they must have logged this ...that mom tried and didn't do a very good job.

For Janet, an inexperienced first-time mother, the instruction from the nurses was invaluable.

> I'm 32 and it's my first baby and I never spent much time around babies ... So I had on-the-job training. I learned

> how to change her in hospital, how to bathe her, how to breastfeed her, everything.

Parents participating in the study by Lissenden (1984) expressed similar appreciation of nurses' supervision of their early caretaking efforts.

At times, however, Janet was deeply upset by nurses' handling of Denise, and protested to assert her rights as a mother.

> If they were rough with her, I would just start to bawl. And they'd say, "What's the matter?" And I'd say, "You're being rough with her; you know she's just a baby." I didn't understand that she was tougher than I thought she was and they knew what they were doing and I shouldn't have misjudged that. To me, it was mine and I didn't want mine treated that way.

Jim and Sharon welcomed the increasing responsibility they were given for Melissa's care.

> Jim: I changed her and Sharon changed her ... We also fed her ... When she moved on to [the next] nursery, then we had almost total control if we wanted to.

Beth and Philip took their caretaking responsibilities even further when doctors mentioned the possibility of Martin's discharge.

> Beth: I said, "I need to get in there up to my elbows as far as learning Martin's care." And so I ... got babysitting for longer periods of time so I could spend more time at the hospital. And Philip was really adamant about going in and changing trachs in the evening. They would hold off doing Martin's trachs so he could do it.

Despite their daily practice in caring for their infants, some mothers felt anxious about their ability to be their main caregivers when the day of their discharge arrived. Barb's body expressed her tension on the day she brought Annette home.

My stomach was in total knots.

Janet's unease about caring for such a small, fragile baby was compounded by her ill-health on the day of Denise's discharge.

> I was just really run down and I was hoping they could keep her for a few more days because I never felt I could cope with her like that .... When she came home I still found her quite tiny and I was still quite afraid.

Summary

Although fulfilling its purpose as a facility for promoting the survival and health of high risk infants, the NICU also proved to be an environment of distress to parents. They had to contend with the unhealthy levels of noise, heat and in one NICU, overcrowding. They were intimidated by the sight and sound of the equipment, as well as its presence as a barrier between themselves and their babies. They endured anguish while their infants were critically ill. Finally, the parents experienced anxiety as they hesitantly began to assume more fully their roles as mothers and fathers of their babies.

That these parents persevered in their frequent visiting despite the many stresses they experienced, can perhaps be attributed in part to the fact that they had all, as Pam commented, "been through so much" before they finally delivered their babies. As a result, each couple had a tremendous investment in helping their infant to live and grow toward health. This may have been reflected in the parents' efforts to communicate with their babies through caretaking activities, and through nurturing activities such as stroking, holding and talking to them. According to Evans (1985) these activities may have had profound effects on some fathers. In the case of the first-time fathers she studied, touching and feeding their premature babies appeared to confirm their commitment to fatherhood.

Nevertheless, the apprenticeship in premature parenthood which parents in this study experienced in the NICU, did not adequately equip them to deal with the tribulations they underwent after their babies came home to take their places as family members.

Theme 3: The Post-Discharge Period - Problems, Increasing Competence and Tentative Optimism

Introduction

Parents and infants, whether fullterm or premature, experience difficulties in adaptation during the first weeks and even months, after the infants' homecoming. What distinguishes the experiences of parents of VLBW premature infants in the post-discharge period, are two factors. Firstly, parents confront the infant-related problems that arise with feelings of apprehension that have carried over from the period when their babies were seriously ill in the NICU. The second factor relates to the fact that in many cases, VLBW premature infants are subject to physical problems and developmental delays by virtue of their extreme immaturity at birth. As a result, the first months and even the first few years of their lives at home can be distressing for their parents. Such was the case with four of the five couples in this study.

Parental Coping with their Infants' Problems

Feeding problems. Ensuring that their infants received the necessary nourishment proved frustrating for most parents. Several babies still possessed underdeveloped sucking and swallowing reflexes, lengthening feeding times to 1 and even 2 hours. Tiring from their efforts, infants often fell asleep before they had received the required amount of food. Parents had to experiment with different types of formulas until they and their paediatricians agreed on one that appeared to be suited to the infants' needs.

None of the mothers was able to breastfeed their babies for more than a few weeks after they arrived home. Neither Barb nor Sharon attempted to breastfeed even while their babies were in the NICU. Because Barb had returned to work a week after leaving hospital, it had not proved possible for her to breastfeed Annette in hospital nor to express milk with the use of a breast pump. Sharon would have preferred to breastfeed Melissa in the NICU but she was prevented from doing so by the demands of caring for Seth and by the fact that she lived far from the hospital and did not have access to an automobile during the day.

According to both mothers, neither of their babies experienced feeding problems at home. At the time of the final interview with their parents, both children were eating a normal diet. Annette was then 16.1/2 months old (age adjusted for prematurity) and Melissa was 16 months old (age adjusted for prematurity).

Janet experienced difficulties with breastfeeding Denise partly because of her own ill-health. These difficulties, compounded by that of finding the correct nutritional formula for Denise, combined to make Janet feel overwhelmed by the succession of new stresses.

> I was too sick, I didn't have enough energy to [breastfeed] .... I finished her off on my milk ... after a week [following Denise's homecoming] and we tried her on Similac, we tried her on another, then another and nothing worked. You know, you come home with all this other anxiety and then you have to go through this. And then you finally find something that works.

Despite weeks of effort, Pam was unable to produce breast milk while Corey was in the NICU. She ascribed this to the fact that her emotional distress during the course of his illness had caused her milk to dry up. Corey had feeding problems both in the NICU and at home. He was still not feeding well from a bottle on the day of his discharge. This problem had led the neonatologist to twice raise and dash his parents' hopes for his release in the course of one week. Finally, Pam unilaterally decided to have Corey discharged because his lung condition had responded well to treatment and the NICU staff's efforts at feeding him were having no more success than those of Kevin and herself. Her action appeared to effect improvement in Corey's willingness to feed from a bottle.

> Kevin: He didn't eat that well but we weren't having as much trouble as they thought we were going to have feeding him .... He seemed to take his bottle better.

It was only after 7 months of trial and error that Corey finally tolerated a formula on a continuing basis.

> Pam: The doctor sent him home on Similac and we had it for a while. Then we had to water it down but that didn't work. Then we put him on full strength Prosobee. That didn't work ... We watered it down, that didn't work. Eventually the Porsobee was working .... The doctor said to keep him on the formula for a year. He's also eating normal foods now.

While in hospital, Beth had attempted unsuccessfully both to breastfeed Martin and to express breast milk for storage in the hospital for later use. She had come home feeling tired and her fatigue increased as the family's demands on her increased, consequently her supply of milk dwindled, and she finally discontinued her efforts to produce milk because of the effort involved.

For 9 of the 12 months he had been in the NICU, Martin had been gavage fed, that is, fed via a tube entering his nose and extending into his stomach. As a result, he had had only 2 months of oral feeding before arriving home. Not only was he, like the other four babies, having to learn to suck and swallow, but he was extremely mouth sensitive. It had therefore been difficult for the NICU staff to persuade him to accept the food his body needed and he came home underweight. His parents realized the need to feed him optimally so that he could gain strength. Their own desire was reinforced by constant urging from specialists which seemed to convey a message to Beth and Philip that their efforts to feed and generally care for Martin were viewed as unsatisfactory.

> Beth: That's one difference with the premature baby ... you ... have to say, "Gee, he's getting this and this ... there is the pressure of the paediatrician .... I started to panic as a mother and say, "Let's get 'em, Marty" .... I had to force feed him with a syringe .... When he used to vomit, I'd say, "Oh, oh," and get really frustrated.
>
> Philip: Ya ... there's the pressure: "Well gee, he's not really gaining"... This constant looking at Martin's weight on a weekly basis ... it can be discouraging. Martin doesn't always gain.

Beth and Philip had been informed by doctors that improvement in Martin's condition of bronchopulmonary dysplasia would be reflected in his weight gain. Because, as his parents they monitored his chest condition daily with the help of pulmonary technicians and nurses, the latter hired to assist in Martin's daytime care, Philip and Beth were aware of his slow rate of improvement and therefore did not expect him to achieve quick weight gains, even with the help of the two special formulas he was receiving.

That feeding is a matter of great importance to mothers, can be seen in the fact that 18 of 33 mothers participating in the study by Brown (1983), chose to study topics connected with learning how to feed their premature and other low birthweight infants. Several of the mothers had had difficulty breastfeeding their babies, and infant-centered feeding problems included sleepy babies, infants' inability to suck and the tendency of some to choke or vomit. Certain of the latter problems derive from the fact that premature infants have been found to initially possess very weak or absent sucking and swallowing reflexes (Miller & Keane, 1978). They have also been found to tire easily from the effort of swallowing, as well as that involved in coordinating swallowing with sucking and breathing (Shosenberg, 1980a).

Sleeping problems. Three couples suffered many weeks of broken nights due to their infants' erratic sleep patterns.

Barb: She had her days and nights mixed up for 8 weeks, up half the night and asleep during the day ... I was home so I was up most of the time.

Noel: It was terrible.

At 16.1/2 months of age (age adjusted for prematurity) Annette was still not consistently sleeping through the night, to Barb's puzzlement and concern.

> She just wakes up and cries. I don't know why.

Researchers such as Barnard (1980b) and Drillien (1964) have identified a high incidence of two types of sleep disorder in premature infants even at 2-3 years of age. One disorder involves difficulty in falling asleep and the second disorder concerns waking during the night. The reasons for these behaviours have not yet been conclusively pinpointed.

Will and Janet also experienced interrupted sleep until Denise had developed a regular rhythm of sleeping and waking. After 3 months, Will was able to report:

> It's not so hectic now ... She's more on a schedule; she goes to sleep pretty well at a regular time.

Pam and Kevin had the longest sequence of broken nights. Even 5 months after his homecoming, Corey had still not developed a pattern of long sleep periods.

> Pam: So often people ask how he's doing and I say, "He's a terrible baby, never sleeps, never drinks."

Two months later, Corey's periods of night sleep had extended to 8 hours, enabling his parents to enjoy the same periods of unbroken sleep.

According to Barnard (1980a), fullterm infants initially sleep in blocks of 3-4 hours which begin to merge so that by the time the babies are 3 months old, they are having single sleep periods of 7-8 hours. The findings of one study show that premature babies take longer to achieve the developmental milestone of unbroken night sleep. Goldberg, Brachfeld and DiVitto (1980) found that fullterm infants took an average of 8.2 weeks to develop a continuous night sleep pattern. Healthy premature infants took 11.5 weeks and premature infants born to diabetic mothers needed 11.7 weeks. Sick premature infants required 13.7 weeks. This group consisted of infants who had suffered from respiratory distress syndrome, a condition in which they were unable to breathe adequately on their own because their immature lungs were still incapable of normal functioning (Goldberg & DiVitto, 1983). Annette and Corey had both suffered from this syndrome.

Crying problems. Crying was not a problem for two couples. Martin was unable to make his needs known to Beth and Philip by crying because his tracheostomy prevented him from vocalizing. In the other instance, Sharon reported that Melissa's crying had been minimal.

> They both [Melissa and her older sibling Seth] weren't criers.

The remaining three couples found their babies' crying hard to bear. Whenever Corey cried during his first weeks at home, his parents' fear was reactivated that his crying might be indicating that his lungs were deteriorating again, just as they had in the NICU.

> Kevin: We worried every time he cried, that it was something worse.

Even while they began to learn to encode Corey's crying cues, Pam and Kevin suffered constant loss of sleep from his continuous crying during his first 3 months at home. The paediatrician had diagnosed Corey to be suffering from colic and prescribed medication for him but his crying continued.

> Kevin: We were up all the night, taking turns.

Five months after his arrival home, Corey was still suffering occasional colic attacks with the accompanying crying but two months later he had fully recovered and his crying was of average duration.

Janet and Will had to endure endless crying from Denise during the first 6 weeks after her arrival home. The paediatrician had informed them that she was suffering from colic and they were administering the prescribed medication. After a few attempts to leave Denise with a babysitter, they temporarily called a halt to evening outings because Denise's crying was proving too much for babysitters.

> Will: We would leave and be gone 4 or 5 hours and from the time we left till the time we came back, she was still crying.

By the seventh week after Denise's homecoming, her periods of crying had decreased sufficiently that Will and Janet again felt able to ask friends and family members to babysit for them. In a study conducted by Lissenden and Ryan (1982) a number of parents of VLBW premature infants also reported experiencing extreme distress when their babies suffered from colic and engaged in continuous crying over many weeks. Barb and Noel felt bewildered by Annette's crying and her unwillingness to be comforted that persisted for the first few months that she was at home.

> Barb: After ... about 6 weeks ... she slept good but she still acted up, she really acted up.
>
> Noel: Ya.
>
> Res: You'd fed her, burped her, changed her and all. Did you try to cuddle her?
>
> Barb: Oh yeah and she wouldn't cuddle, she wouldn't take that.

Other mothers of VLBW premature infants have found their babies to be irritable and difficult to console. In general, these problems have been reported more frequently by mothers of these infants than by mothers of fullterm infants (Goldberg & DiVitto, 1983).

Infants' rehospitalizations. Three couples had to experience the rehospitalization of their infants. One of these infants was Melissa. She had progressed faster than most VLBW premature infants after coming home and she experienced only one setback in the subsequent 20 months. Approximately 9 months after her homecoming, she had had to be hospitalized for 6 days suffering from croup. She recovered well but during the ensuing few months, Sharon and Jim has great difficulty persuading her to drink liquids.

> Sharon: For a long time she didn't want nothing to drink. It was a lot for us to get one bottle of milk down her, which wasn't very good.

According to Barb, Annette was discharged as "perfectly healthy" but she developed respiratory problems during subsequent months. After she had been home a few months, she was hospitalized for 5 days suffering from a bad cold. She was so ill that Noel feared she might not survive.

When she had first arrived home, Annette's breathing was so audible that Barb had placed her in her nursery immediately, believing that she herself would be kept awake by the sound of Annette's laboured breathing. Barb did not believe Annette's unusual breathing to be pathology based and resisted when the chest specialist first recommended that Annette be examined under an anaesthetic for the existence of narrowed breathing passages, apparently a common occurrence in premature infants. Part of Barb's resistance originated in her fear that surgical findings might add further to her burden of worry about potential problems Annette might develop.

> I was really upset because it's just another thing I have to look for: this might be going wrong in the future.

She finally agreed when the specialist again suggested the surgical exploration 4 months later. Annette was approximately 15 months old (age adjusted for prematurity) when the procedure was performed. The surgeon found and removed a benign cyst which the specialist later stated had reduced Annette's breathing capacity by approximately 25%.

Martin contracted a number of respiratory infections after his arrival home. In the sixth week Beth had him hospitalized because she was alarmed by his increased wheezing, audible internal chest sounds, recurrent lung infections and a persistent cough. A surgical exploration showed such severe tracheal scarring that there was a minimal opening between the larynx and trachea. However, Martin's vocal cords were found to be moving normally.

At the time of the final interview with his parents, Martin was due to enter hospital for further surgery in 2 months' time. The purpose would be to open the trachea and insert bone or cartilage from another part of his body to maintain the opening and enable it to grow wider.

The scanty research on the rehospitalization of VLBW premature infants shows that the experience is fairly common in this high risk population, and the reasons are similar to those that necessitated the rehospitalization of Melissa, Annette and Martin. Hack et al. (1981) followed 90 babies who had been discharged from hospital. Of this total, 30 required rehospitalization on 51 occasions during the year following discharge, some infants returning to hospital more than once. A majority of the rehospitalizations related to the continuing care of chronic conditions connected with the initial neonatal hospitalization, and secondly, to respiratory and other infections. Aradine, Shapiro & Uman (1980) comment that every readmission of their baby is a stressful event for parents because it arouses painful memories of their babies' previous hospital experiences.

Infants' Developmental Status

All five couples had been contacted by the staff of the high risk infant follow-up clinic and requested to bring their babies to the clinic for periodical assessment of their development status. Four of the couples had done so. Pam had been unable to keep her first appointment because its date conflicted with that of an important examination she had been scheduled to write. Administrative problems within the clinic had temporarily prevented the staff from arranging a new appointment.

Jim and Sharon had received consistently favourable reports on

Melissa's progress and when she was 1 year old (age adjusted for prematurity) they were informed by clinic staff that she had caught up with equivalent fullterm infants in all respects.

Barb and Noel were pleased with Annette's progress in walking and talking and in her general learning ability at 17 months old (age adjusted for prematurity). The clinic staff had examined Annette twice.

> Barb: [Testing] was done when she was 6 months and then a year. They just said she's progressing at I think her adjusted age at the time.

Until Annette was 16 months old, Noel and Barb had not allowed her to play with other children for fear that she might contract infections. Following the surgery in which a cyst was removed from a breathing passage, Annette contracted two colds one month apart but did not need hospital care.

Will and Janet had been informed by the clinic staff that their most recent examination of Denise had shown her height, weight and motor development to be in the normal range. They themselves were delighted that 7 months after arriving home, she was at last feeding well, was increasingly sociable, had begun to vocalize throughout the day, was physically active and had commenced teething. Her age was then 6 months (adjusted for prematurity). Their only concern was the serious cold she had contracted the previous month and yet another one she was suffering with respiratory complications at the time of the final interview with them.

Even without confirmatory examinations by clinic staff, it was clear to Pam and Kevin that Corey was making progress 5 months after his homecoming. His feeds were taking less time, he was no longer contracting infections and he was producing his first tooth. He was beginning to vocalize and to interact enjoyably with family members and with strangers. At 8 months of age (adjusted for prematurity) he had begun to stand with the aid of a walker.

Philip and Beth had initiated Martin's discharge from hospital partly because they had been warned confidentially that he would not receive quality care after his impending transfer to the children's ward, and partly because they feared his psychosocial development was being impeded by the institutional setting in which he had lived since his birth a year before. They were therefore gratified to see him improving in this and other areas a few months after his arrival home.

At 13 months of age (adjusted for prematurity) and 4 months after his homecoming, Martin was contracting infections with reduced frequency and Philip saw other positive changes as well:

> He has just changed like night and day. He's much, much stronger. He's three times as alert. He's very curious, he's sticking things in his mouth .... I've always been close to him .... but I certainly have become much warmer now that he has got a personality of his own that's developing.

Even on the day of Martin's discharge, Beth had felt that he and she were still semi-strangers. She was therefore delighted by the increasing attachment to her which he appeared to be displaying 4 months later.

> It's neat ... he's relating to me more.

Beth was also encouraged by Martin's manifested wish to be more physically active and instructed the nurses assisting with his care, to place him in areas of his home that would permit him freedom of movement.

> He's up more. I make a point, if any new nurse comes in, I'll say, "I don't want him in the crib."

The follow-up clinic's most recent assessment had shown Martin to be 5 months behind his peers in motor and mental development.

When Martin first came home, his parents were not sure how long he would live. In light of his improvement a few months later, Philip stated:

> It's definitely starting to come across that he's going to be here for a long, long time.

Parents' Lack of Information about Premature Infants

The majority of parents felt their lack of knowledge about the normal development of premature infants most acutely during the first months following their babies' arrival home. Mothers who had received a booklet on premature infants from NICU staff, reacted to it with varying degrees of enthusiasm.

> Sharon: I ... read that premature infants shouldn't go to shopping malls for the first little while and this and that ... Helps you understand things more.

> Janet: We did get a little book on premature babies ... and I just would have liked to know more ... There ... weren't any handouts.

Jim and Sharon were reassured by Melissa's good progress both in hospital and after coming home, and particularly by the good reports from the follow-up clinic. They therefore did not see the need for additional information on premature babies.

Beth and Philip had been assertive parents from the outset, insisting on clear explanations from specialists, doctors and nurses about the health problems of Beth and later Martin. Philip, in particular, had spent a great deal of time reading in the area of prematurity and more specifically, on the topic of infants with bronchopulmonary dysplasia.

Pam had hoped that the public health home visitor would be able to provide her with information about the developmental course of premature infants, but this had not happened. She commented: "I've had two visits from her ... but I don't know, she doesn't tell me anything." Pam also felt discouraged after attempting to obtain information from staff at the local public health clinic.

> I got hold of the head nurse and a couple of other ones and I was first asking them for information. They have a little library and they have no information in there probably about premature babies.

Some parents felt deep, continuing anxiety about their lack of knowledge regarding possible health hazards for premature infants, developmental milestones to watch for, and when they could expect their babies to have caught up in development with fullterm infants of comparable age.

Although Kevin had appreciated the literature on prematurity supplied by the NICU staff, it had not supplied all the information he needed after Corey came home.

> Kevin: Even up to a few months ago, I didn't know if I could go outside with him ... You don't know what he can tolerate and what he can't.
>
> Pam: I thought when I took him home when he was 3 months old, well maybe now he'll catch up, you know. But I don't know when he's going to. You don't have any information on that?
>
> Will: I don't know anything about premature babies. People should do more studies to find out will they be like normal babies when they get older.
>
> Janet: I know every baby is an individual but still, they have basics: a 4-month old will do this .... whereas with Denise, even though she's 4 months, she's only 6, 8 weeks .... You never really know what age she's going to be doing things compared to a fullterm baby ... I wish I had ... maybe newsletters ... about what ages or stages [premature] babies start to do different things.

To lessen her feelings of uncertainty engendered by lack of informational guideposts, Janet requested information from the researcher. On one occasion, she asked whether any of the other infants in the study were walking yet and if so, at what age they had commenced to do so.

Barb's desire for information about premature infants was dominated by a need to prepare herself for the worst by knowing in advance what possible problems Annette might develop.

> Res: Do you think you know enough about how premature babies develop and how they're different from fullterm babies?
>
> Barb: Not really, because there are so many things that she probably could develop.

Because the public health home visitor lacked knowledge about premature infants, she was of little help to Barb.

> It was more a traumatic experience for her because it was her first premature baby so she had more questions than I had.

Like Barb, Pam worried aloud that Corey might possibly develop some aberrant characteristic. Following a comment from the researcher that most premature infants do not appear to have problems in childhood or later in life, Pam asked, "You mean he won't be hyper?"

When the researcher informed Pam, Janet and Barb about two books on premature babies which had been written specifically for parents, Pam and Janet requested the titles and authors. Barb did not respond.

The need for information about the various aspects of premature infants' growth and development, was also expressed by a majority of the 33 mothers who participated in a study by Brown (1983). Some of these mothers may have required the information to allay fears similar to those expressed by Barb and Pam, that their premature infants might not develop normally in all respects. Duhamel et al. (1984) comment that many parents fear that their premature babies' physical, intellectual and emotional development will differ from that of fullterm babies.

Siblings' Reactions to the Arrival of the VLBW Premature Infant

Three couples had older children in addition to their VLBW premature infant: Kevin and Pam, Jim and Sharon and Philip and Beth. This meant that these parents had to deal with the impact of their special baby's arrival on their older child and in the case of Beth and Philip, on their two older children.

Jill initially appeared threatened by having to share her parents' love with Corey.

> Kevin: She seemed to think at first he lived in the hospital. I guess when he came home she was a little jealous at first.
>
> Pam: She wet the bed a couple of times.
>
> Kevin: Yes, she was out of that stage and then she did it a few times.
>
> Pam: Sometimes she'll tell me to put him to bed.

By the fifth month after Corey's arrival home, Jill appeared to have accepted Corey and welcomed him as a playmate.

> Kevin: Jill will sit on the floor and play with him as long as he wants to stay down there.
>
> Pam: She likes him a lot ... She can't wait till he gets bigger to play longer.

Seth also showed signs of being upset at having to share his parents with Melissa, but his behaviour toward her became more aggressive than that of Jill toward Corey. At first, when Melissa was in the NICU, Seth displayed affection for her.

> Sharon: In the hospital when we went to see her, he always wanted to hold and touch her.

Seth's attitude changed after Melissa had been home a few months, and had begun to receive marked attention from relatives and friends of his parents.

> Sharon: He started being jealous. He wasn't acting jealous, he was doing things he wasn't supposed to, like throwing something, things like that. He was just trying in any way to get attention ... We just ignored it .... and after a few days he was fine again .... And now in the mornings he's up and he gives her her bottle.

One of the possible reasons for Seth's improved behaviour toward Melissa may have been the fact that his paternal grandparents were once more giving him the attention they had transferred to Melissa.

> Jim: [With my parents] ... Seth used to be the apple of their eye but then Melissa came along and they turned to her .... But my parents aren't as bad anymore ... as in the past.

Two months after furnishing the above information, Sharon and Jim described further troubled behaviour which Seth had recently been exhibiting. At this time Melissa had been home for 17 months.

> Sharon: [He's] being a real pest.

> Jim: Ya, getting in the way of her and so on. She starts to go somewhere and he'll pull her back. He doesn't mean to hurt her but often he's hurting her.

> Sharon: Or push her out of the way. Sometimes if she does something kind of babyish, he'll go along with it too, and act the same way.

Seth's more belligerent behaviour toward Melissa as she becomes more active, appears to be a common phenomenon. In their research, Sostek and Read (in Trause & Irvin, 1982) found that sibling's hostility toward infants increased as the latter approached toddlerhood. One possible reason is that as infants begin to learn to walk, they once more become the centre of adult attention. A further possibility is that older siblings may begin to feel threatened when they see the younger children begin to develop skills more closely approximating their own. They may then find it necessary to assure themselves that they are the superior ones by demonstrating their physical superiority over their younger siblings.

Philip and Beth had to deal with the emotional and behavioural responses of their two older boys to having a new and very sick family member at home. When the boys saw how much of their parents' time was being consumed by Martin's care, they chose to express their feelings of parental deprivation in distinctive ways.

During the first weeks that Martin was home, both of his brothers showed concern for him, letting Beth know when he needed her and comforting him when he coughed. Approximately 2 months later, Stephen, aged 2.1/2 years, developed a fantasy baby and a fantasy father in his stomach. He also clung to Beth more, trying to get her to pay less attention to Martin. On one occasion, he painted a room with paint he knew had been intended for a different room.

During the same period, John had begun to watch television with increasing frequency. Philip and Beth interpreted this development as his way of seeking companionship and reluctantly accepted it only because they saw it as a temporary situation. They both saw John as being particularly nurturing toward Martin, for instance, giving him his bottle.

As Martin's health began to improve from the third month, so did his relationship with his brothers.

> Philip: They're starting to play with Martin and he really is starting to enjoy them. When he hears the two boys come in the room, he really beams.

Four months after his homecoming, Martin was well enough to spend periods of time away from his upstairs bedroom. This enabled him and his brothers to engage in a variety of activities in the living room. Nevertheless, Beth believed that Martin's inability to vocalize because of his tracheostomy, had impaired his relationship with his brothers who were realizing he was different from other babies.

> There's a distancing between Martin and the other two and that's because he can't speak. And Stephen will say when he sees other babies, "Mom, that baby didn't have a drink and he can cry."

Beth and Philip saw the two older boys as suffering two further difficulties. The neighbourhood had few children with whom they could make friends, consequently they had had to look to their parents for companionship more than most children do. Because of the many demands made on them by Martin's care, Philip and Beth had been unable to satisfy the boy's expectations, although they attempted to continuously assure the boys of their love for them.

> Beth: Ya, they've paid the price ... I'm scattered and ... I can't focus on them. Our relationship, it's hard to get back to it sometimes cos I've spent .. 5 months doing all the things that need to be done with Martin.

> Philip: I don't think there's another family around that expresses its love as much as we do to our two boys. I don't think a day goes by that we don't make sure that our children are loved and we tell them that directly. Sure they're insecure, there's no question about it, but I don't think we could be anymore loving toward them, really.

The boys' second difficulty related to the fact that they had been required to adjust to the steady flow of parttime registered nurses needed to provide daytime care for Martin.

> Beth: Having the nurses here, the kids feel it too: "There are strangers in my house." They still react by having temper tantrums or behaviour things [sic], whatever they need to go through.

It was not until the nurses had been working in their home for 4 months, that the boys began to talk to them.

Although some of the stresses experienced by John and Stephen were unique to them as siblings of a child with a chronic illness, they, together with Seth and Jill, manifested behaviours that have been observed in other siblings of premature-infants. Brown (1983) states that 10 of the 33 mothers in her study chose to seek out information with regard to the effect on siblings of a low birthweight infant's arrival in the family. These mothers were encountering displays of jealousy by the older children as well as other forms of behaviour signalling distress.

Parents' Personal Stressors

Concurrently with the many unsettling events relating to the health problems of mothers and infants, parents also had to cope with difficulties in their personal lives.

Unemployment. Most parents were either directly or indirectly affected by the current unemployment situation. Will and Janet felt the strongest impact. Will was the only father to be unemployed for a significant period of time during the present study. He had lost his tradesman's position in the construction industry 4 months before Denise's birth, found employment 10 days after she was born and again ceased to be employed 8 months later. Janet had intended to take a year's maternity leave with unemployment insurance payments as her source of income, but 5 months after Denise arrived home, she was called back to fulltime employment on pain of having her position eliminated if she refused. Will, who was then unemployed, assumed the role of fulltime homemaker.

Noel, also a tradesman, had lost his fulltime position as a result of the prevailing economic recession. He then decided to become self-employed and had been able to obtain contracted work on a fairly steady basis.

Although Jim never at any time lost his position as a partsperson in a car dealership, he had been forced for some months after Melissa's birth to work a four-day week instead of the usual five-day week because of poor car sales. He also endured a period of uncertainty when he feared he might lose his employment altogether.

Neither Kevin, a compositor on a newspaper, nor Philip, a manager in a large industrial company, were aware of any threat to their employment. However, Philip was emotionally affected by the insecurity of fellow workers which was being engendered by the company's cost-cutting measures.

> Right now the company's going through a terrible transition with the economy so poor .... I know I'm not losing my job but there are people around me that are being damaged badly by all the things that are going on. Sort of rubs off on you, you can't help it.

Not only did parents have to suffer the emotional strain associated with insecurity of employment, but they had to deal with financial strains as well.

Finances. Couples were faced with financial problems of varying magnitude, Janet and Will and Beth and Philip were the only two couples free of monthly mortgage payments but even they had to stretch barely adequate incomes to cover the extra expenses that were incurred in connection with the hospitalization and later home care of their babies. For all five couples, frequent visits to the NICU entailed increased expenditures on gas and often the cost of light meals at the hospital. Even with the reduced parking rates offered by the hospitals, most couples incurred additional parking costs.

Janet and Will had always carefully budgeted their money, consequently when Will lost his employment after Denise's arrival home, they had savings to supplement Janet's earnings and Will's unemployment insurance income, should that prove necessary. Their major expense was Denise's formula which cost them a total of approximately $500.00. Looming on the horizon, however, was the need for Will to initiate a change of occupation because of a back problem which was aggravated by heavy physical work. His career change would entail fulltime study with its concomitant loss of income, and the daily absence of both parents from the home would necessitate the hiring of a babysitter. Will and Janet therefore wished to retain their savings to meet these future expenses.

Because Sharon had never worked outside the home, Jim's salary was the sole source of family income and was barely sufficient to cover mortgage payments, basic living expenses and the expenditures connected with visiting Melissa in hospital and providing her formula. The cost of her formula was more than Jim's salary could cover.

> Sharon: We managed through Family Allowance 'cause it would just come when her case of formula was empty. So we just made it.

Barb and Noel had been living on a tight budget for the past 3 years. Barb had had fulltime employment before Annette's birth, had spent the first year after Annette's arrival home as a fulltime homemaker, and had then resumed parttime work. During Annette's first year at home, she had required special formulas costing approximately $90.00 per month. Even though that expenditure was no longer necessary, Noel and Barb were still having difficulty meeting all their financial obligations, especially after a sudden tripling of their property taxes.

> Barb: On the fifteenth of the month we wonder how we're going to make the mortgage payment but something usually happens that we get by.

Like Sharon, Pam had not worked outside the home since her marriage and Kevin's salary therefore had to stretch to meet monthly mortgage payments as well as the $35.00 per month cost of Corey's formula. During the week that Corey was critically ill, Kevin stayed off work for 5 days but lost 3 days' wages because he only had 2 days' vacation with pay due to him. He and Pam also incurred an unexpected, large outlay when their car developed mechanical trouble. They lived so far from the hospital that it was impractical for Pam to attempt to travel to and from the hospital daily by bus.

Despite holding a managerial position in the company which employed him, Philip stated that he had a very limited bank balance. This was partly due to the fact that Beth had chosen to be a fulltime homemaker until the children reached kindergarten age. Fortunately for the family, Philip's company provided a generous medical plan which paid the salaries of the registered nurses helping with Martin's daytime care until he was two years old, and perhaps longer. The plan had also paid the cost of his formulas for the first 3 post-discharge months but since that time it had been costing Philip $112.00 per month to provide Martin with the two special foods he needed. Although the plan also covered babysitters' fees, it did so retroactively, requiring Beth and Philip to pay babysitters, submit a claim, and then endure a long delay until the company reimbursed them.

Strains on personal, social and family life. Parents' lives were centred around visiting their infants during their hospitalization. After the babies joined their families at home, they continued to absorb much of their parents' time and energy. Parents also had to attend to their many other responsibilities both within the home and outside it. All these demands left most parents with depleted physical and emotional resources. These limitations, together with prescribed precautions to safeguard their babies against infection, affected various aspects of parents' lives.

Jim and Sharon were able to resume their normal way of life sooner than the other four couples. Jim, more than Sharon, remembered feeling housebound during the first weeks after Melissa's homecoming. Once her progress became apparent, however, they took her and Seth with them when they visited friends and family members, their main social activity.

Other parents besides Jim felt confined in their homes during the first weeks and even months after their babies arrived home. Barb remembered that she and Noel did not go out very much during the first months after Annette's arrival home because it was wintertime and they were unwilling to take such a small infant out in sub-zero weather. Initially this was no hardship for them because they were both ready for a slower pace of life after several years of continuous social activity. A year after Annette's homecoming, however, they were feeling isolated from friends because of the need they felt to still protect Annette from infections that their friends' children might possibly bring into the home.

> Noel: We don't see our friends as frequently as we used to because I've been away and it's been cold. And if their kid's got a cold, you don't want them around because of Annette, she might get a cold. It does affect it [their social life] quite a lot.

Barb described herself as being "more short-tempered" than she had been before Annette's birth. This may have been the cumulative result of the many stresses she had had to cope with in connection with Annette's birth and subsequent developmental passage. Barb expressed particular frustration with her inability to discipline Annette to her own satisfaction.

I've slapped her on the behind and sometimes that works if

> she goes into a hysterical fit or whatever .... I think she did that most when she was very little .... And she still does that sometimes too. She has this little thing of temper tantrums, and she gets a little slap on the behind when she does that.

Two months after Martin's homecoming, Philip and Beth felt oppressed by the limited opportunities they had to spend time together outside their home.

> Philip: What I'm feeling is the pressure of being caged in because we are very restricted in getting out by ourselves.
>
> Beth: The winter was exceptionally long. And I have to admit having people coming into the house is a godsend for that reason.

On one occasion when Beth and Philip were able to dine out, their enjoyment was marred by fatigue.

> Philip: We're so darn tired ... A couple of weeks ago ... on a particular night, I think we spent an hour away from home. We were just too tired.

By the time Martin had been home for 4 months and was showing marked improvement, Philip and Beth were able to spend the occasional evening out together.

Beth felt not only socially but intellectually deprived. The considerable amount of time needed for Martin's care had left her with little opportunity to attend classes on topics of interest to her.

> I have pretty well shut down my own personal learning this past 2.1/2 years. I really do miss taking courses. This world here gets me down because I don't get out enough, don't have enough stimulation.

Beth was also aware that family relationships had been strained by the many circumstances relating to Martin's birth, hospital stay, and home care.

> When our family get together, we're all really irritable. We don't know how to be together. There are lots of struggles.

Both Will and Janet reacted to their initial weeks of confinement at home with Denise by becoming depressed.

> Will: I went for a check-up today and the doctor could only come up with the fact that my blood pressure was low and he said ... probably the reason ... is because of the depression .... Basically you just go to work, come home to babysit. We've really had no chance to go out anywhere.
>
> Janet: I told my mom and I cried, that when I go out somewhere, I want that period to last, I don't want to go home. A lot of mothers have told me that's normal after being cooped up but it bothered me I didn't miss Denise at all. During the day I basically stay home with her ... Doing something with her, that's a big production ... Babies don't like getting dressed ... and getting her in the car seat, she hates that, and with the crying and everything, I'm too uptight.

Not only were both Janet and Will tired from lack of sleep and stressed by Denise's constant crying, but Janet had suffered from a number of health problems since her discharge from hospital. These included pelvic inflammatory disease, vaginal infections, bladder infections, and loss of appetite. The fact that her depression lasted for 4 months can probably be attributed to her having to cope with not only the after-effects of a caesarean section and other physical problems, but also with the totality of all the other problems she encountered in Denise's early months at home.

The cumulative stress caused by Denise's seemingly endless crying and feeding problems at times caused Janet and Will to feel a combination of desperation and resentment toward her. On one occasion when all her attempts to comfort Denise had failed, Janet expressed her pent-up feelings in an act of mild aggression toward her.

> Sometimes you're afraid of what you're going to do. Sometimes your mind just snaps and you get so angry. [I] told Dr. .... "I didn't know what to do with her and I kind of pushed her ..." I cried so hard.

Will recalled occasions when he felt close to breaking point because his many efforts to calm Denise had proved fruitless.

> [You have to] get out, gather your own thoughts and get your own individualism back, otherwise you feel caught up, like she's depriving you of something. Your system is down, you're down, you just don't have the toleration for things that you're not used to ... There were times when I was getting frustrated to the point that "I'm doing the best I can and why are you doing this to us?" And you feel your teeth starting to crunch and you realize you have to get a hold on yourself.

Three months after her homecoming, Denise had developed a more regular schedule of sleeping and feeding and was crying less. This freed Janet and Will to request relatives and friends to babysit so that they themselves could spend occasional evenings away from Denise. They had also begun to take her to church services and on visits to family members.

Kevin and Pam were virtually housebound for several months because of Corey's unsettled patterns of sleeping and feeding, and the need to care for his older sister Jill. Five months after Corey's arrival home, his parents were still exhausted by lack of sleep. They were still unable to invite friends to visit them very often because of his erratic hours of sleeping and waking. At that point, they had not been out alone since the day of his birth.

Pam:	We just said a while ago that if somebody wanted to give us a gift, it would be to have just one day ...
Kevin:	Yes, just to sleep in and have a meal together, the two of us, with no interruptions.

After Corey had been home for 8 months, Pam found a reliable babysitter for him, enabling Kevin and herself to go on outings alone and with Jill.

Other parents have experienced several of the problems described by parents in this study. Shosenberg and Lennox (1985) present the recollections of two parents:

Jackie:	Having a two and a half year old and a preemie at home, it just seemed that I didn't exist anymore. The first month was hard because it was Christmas and the second month was hard because we couldn't take her outside to visit anybody. It was just us in the house all day.
George:	I was afraid of someone bringing something into the house that she could catch ... I wanted everybody to come over to see my daughter but I would have to ask, "anybody sick in your family?" I told them we couldn't afford to have anybody here that is not healthy. We can't take that chance.

How Parents see their Infants' Future

Silcock (1984) reports that 70% of the mothers she interviewed expressed strong concerns about their babies' future development at the time of the babies' discharge from hospital. A number of parents in the present study still felt those concerns even months after their infants had come home, while other parents felt more optimistic.

When expressing her view of Annette's future, Barb's apprehension prevailed over her optimism and went much deeper than that felt by Noel.

Noel: I worry now and then but I think she'll be OK.

Barb: [Worry] will probably always be there till she's 30.

More positively, Barb expressed a willingness to work as a partner with the follow-up clinic in helping Annette surmount whatever developmental problems might emerge.

> I feel that if there is going to be a problem with learning or whatever, they'll catch it sooner than I would. This way we can do the proper things for her .. so she isn't behind or slow.

On a rare occasion, Barb expressed a belief that Annette would develop normally.

> All of them don't make a clean escape ... and I just think ours is going to so I don't worry about what's in store.

Although the likelihood of Denise developing problems arising from her prematurity hovered as an ever-present shadow in their minds, Will and Janet were prepared to think and act positively if it became a reality.

Will: I really look at it as just take it step by step and if we see she's slower, then we have an exception. I think we always have it at the back of our minds that she could tend to have problems because of what she went through. As long as she's happy and does something with her life.

Janet: Because we live in the city .... if your child is slow ... there's so many programs [to help her].

The fears of these two couples that signs of abnormal development might surface in their babies even after professional examinations had revealed that they were developing normally, have been observed in other parents of VLBW premature infants (Barnard, 1980b; McCarton, 1986).

Sharon and Jim, as well as Pam and Kevin, expressed complete optimism about their babies' future progress.

Jim: As far as we can see, she's going to lead a totally normal life, the same as any other child.

Sharon: Just cos they're premature doesn't mean nothing.

Pam: I once said to the doctors ... that they had saved him and they said ... "He did it, he's the fighter ... if he wants something, he'll get it." And that's the way he is now. I think he'll be a bit small but I don't think anything's going to hold him back.

Kevin: I think he's going to be fine, oh ya .. he's just a normal baby as far as I'm concerned.

Philip was able to see Martin's future on the basis of both his own perceptions of Martin as a person, and of possible medical prognoses.

> I'm cautiously optimistic that Martin will be certainly a person that will be able to get through life without too many

> difficulties. I think he's going to be a person with very strong convictions and strong will. I think from a medical standpoint, he'll still be burdened with medical problems, probably throughout his entire life .... I also think it will be very naive to believe that Martin's going to have a voice that sounds normal.

Summary

For parents of both fullterm and premature infants, the arrival home of a new baby means that the family is now complete. For the parents in this study, there were two additional meanings. Firstly, they believed that they could at last fully assume their roles as parents after sharing them with the NICU staff, and secondly, they believed normal life could commence for themselves as individuals and for their families, both as individual members and as a group.

Unfortunately, the five couples in this study had to wait a significant period of time before beginning to feel competent as parents, and before their personal and family situations began to provide them with more rewards and fewer stresses. For a number of reasons, parents had to call on the help of professionals more than they had anticipated would be necessary. Most of the babies had difficulties with feeding and with settling into regular daily routines. Secondly, most of the parents had little basic information about the problems and the developmental course they should expect from VLBW premature babies, consequently the majority felt the need to consult professionals on a continuing basis during the first post-discharge months. In the case of three couples, they had a further need to call on the expertise of professionals when their infants became ill enough to require hospitalization.

Parents' hope that they and other family members could commence to lead normal lives after their infants had arrived home, was not realized as soon as they had expected. In only two families had this been achieved by the time of the final interview with them 7 and 8 months respectively after their infants' homecomings. Even in the case of the two couples whose babies had been home 16 months, there was still disharmony, caused in one case by sibling resentment of the new baby. In the other instance, a mother's pessimism regarding the future outlook for her infant daughter may possibly have been reflected in her unsatisfying relationship with her.

Despite the perinatal and postnatal hazards their infants had encountered, the majority of parents felt guarded optimism about the future prospects for their physical, emotional and intellectual development.

Theme 4: Parent-Professional Relationships - Personal and Institutional Complexities

Introduction

Both within the hospital setting and outside it, professionals played a major role in parents' lives. Parents recalled some interactions with professionals as satisfying, while other proved to be distressing.

Some parents seemed to view their concerns as too unimportant to merit a busy professional's time and attention. This stance may have been a factor prompting some parents to act as apologists for professionals whose behaviour had proved disappointing to them.

A common theme underlying the majority of parents' complaints was the lack of empathy displayed by professionals. Parents saw this manifested in several ways in both the behaviour of individual professionals, and in various institutional practices.

Within the Hospital Setting

Professionals' treatment of mothers as patients. Mothers' accounts of their stays in hospital show the profound role that the behaviour of nurses and doctors played in making their stressful situations either more bearable or more painful.

Sharon's memories of the hospital staff she dealt with prior to and after Melissa's birth, were predominantly positive. She praised her obstetrician and she and Jim recalled with gratitude the doctor on duty when she was admitted to hospital in great pain. The doctor recognized her from her hospitalization 3 years previously when Sean was delivered by caesarean section. Because the doctor remembered Sharon's physical problems arising from possessing only one kidney but two uteruses, she was prompt in ordering the most appropriate treatment for Sharon until the obstetrician arrived. With regard to the nurses who cared for her, Sharon stated:

> There were some you didn't really care for and some you got on with really well.

Barb's memories of the nurse-midwives on the maternity ward were mainly positive.

> They had those - what do you call them - yes, midwives. Well, they're nurses now ... and I had some very nice nurses.

On the other hand, the apparent lack of interest displayed by her personal doctor left Barb feeling hurt and abandoned.

> She wasn't around all that much. She came once and she checked me over and didn't really say anything. After that I really didn't see her. She might have popped in for 5 minutes for a "How are you?" "Fine." "Goodbye." .... I'll never go back to her.

Janet's introduction to maternity patient status was not a propitious one. Although she had been warned that her doctor was not noted for his tact, his sharply worded response when she telephoned him in panic, left her feeling she had been attacked by the very person she had looked to for support.

> When I phoned the doctor I said, "I think my water broke." He said tense, "Well, what in hell are you waiting for?" It was very brutal ... I was upset and I started to cry.

During the days in the intensive care unit prior to her delivery by caesarean section, Janet felt reassured by the efficiency and the attentive attitudes of the staff.

> My treatment was excellent ... and the nurses just went all out. And the anaesthetist was very personal [sic].

While recuperating from her surgery, Janet encountered the occasional nurse whose inability to deal sensitively with patients, was a source of distress to herself and other mothers.

> I wasn't the only mother that felt [upset] ... because the other girls I got to know - each and every one of them at different times had a little fight with a nurse ... and in most cases it turned out to be the same nurse.
>
> Will: She may have been a good nurse but she didn't have the personality to deal with a time like that.

When Pam was admitted to hospital, the staff either did not perceive or discounted, the emotional turmoil her bleeding had aroused in her.

> I thought I was bleeding quite a lot and I was scared.... I was just panicking that I was going to lose it ... I panicked 'cause I was going into shock .... And then when I went to the hospital, they told me, "Well, you're not bleeding that much."

Pam also recalled with anger an incident which she believed may have precipitated Corey's premature birth, and which she attributed to the unprofessional conduct of the staff. The situation had evolved from her discomfort after experiencing constipation for several days.

> The nurse gave me a laxative. She had to phone the intern .... my doctor was away .... As I was swallowing it, she says, "Your uterus may start contracting." I went into labour hours later. I was shocked. That nurse ... I thought she was stupid. She got the doctor ... [he] had probably not even read my chart or known my history... You would think that things shouldn't be given out because we're all high risk pregnancies there. I think they should have said, "Look ... you're a high risk pregnancy and these [the medication] could cause your uterus to contract. I think you're just going to have to bear it." I would have, probably.

After Corey's delivery by caesarean section, Pam's longing to see him was so strong that she decided to do so without waiting for Kevin to arrive and transport her to the NICU in a ~~wheelchair.~~ She felt hurt when her doctor interpreted her intent as arising from a neurotic need to be self-sacrificing, rather than from her need to see the baby she had endured so much to carry and deliver.

He said, "Don't be a martyr."

Pam's assessment of the quality of the nursing she received, was balanced.

> Some times were hard but I would think that on the whole they [the nurses] were very good.

Of all the five mothers, Beth's experiences as a patient during the 5 weeks she spent on the high risk ward of a secondary hospital, appear to have been the most distressing. One reason related to a mistaken prognosis on the part of the obstetrician. He had informed her that because she was only in the second trimester of her pregnancy, there was little chance that she would deliver a live baby or if she did, that the baby would probably not survive. He was proven incorrect on both counts, with the result that a few hours after delivery, Beth and newborn Martin had to be transferred to a tertiary hospital so that Martin could receive specialized neonatal intensive care. Philip still felt angry about the incident as he recalled it 18 months later.

> It was quite an orchestrated affair to transport Beth after she had had Martin .... Why wasn't she transported at the 20th week? .... The doctors know ... they have no facilities

> at all for caring for premature children of .... Martin's size .... [This] is a case where a fellow ... obviously thought he was doing the best that he could but it just wasn't good enough in my mind .... It was just stunning to hear [the neonatologist] saying, "It's a pity I didn't know about this case earlier."

Similar criticisms of obstetricians were made by fathers interviewed by Lissenden (1984), one of whom stated:

> He had no business to book my wife into a hospital with no NICU facility. When he put in the cervical stitch he must have known it would be a premature birth.

Beth had come to view the fallibility of the obstetrician in a more accepting frame of mind than had Philip. She was unable to maintain this stance, however, when recounting what she had experienced as the insensitive behaviour of doctors and nurses toward herself and other patients on the high risk maternity ward. One instance occurred when she discharged herself from hospital and returned a week later because her hemorrhaging had worsened. She was then asked by a doctor what she had done to cause the continuance of the hemorrhaging. The accusation she saw implied in his question exacerbated the sense of guilt she was periodically experiencing that the hemorrhaging was indeed, somehow her fault. Because she was aware of her own tendency toward self-blame, she was able to empathize with other patients who were experiencing similar thoughts and feelings.

> One of the worst feelings I experienced and I saw women experience it time and time again, was trips of guilt, that we were to blame for this hemorrhaging... Young women .... many of them young girls having their first child .... were

> having complications with regard to smoking or some external thing they were doing.

Beth was also affected by the patients' discontent with the treatment they received from the doctor on his daily rounds. He appeared oblivious to the women's need for adequate time with him to pose questions and have them satisfactorily answered. Beth was the only patient who insisted that he stay and answer her queries; the other patients appeared to lack her confidence and remained frustrated and anxious.

> There was a lot of damaging stuff being done on those women. They would wait all day for the doctor to come and the doctor would spend two seconds with them and then he would leave. And they would get really rebellious against him, like "What are you doing for me?" .... "What's going to happen to me and my child?" and nobody really giving them the information. I like taking responsibility for myself and my health .... so ... I'd say to the doctor, "I have 103 questions for you today" as a joke but not really, and I would demand that he talk to me.

Beth saw insensitivity in the tendency of some nurses to treat her hemorrhaging in what she perceived as a flippant manner. She responded in a manner to match theirs, hoping her mild sarcasm would convey that her condition was a matter of concern to her.

> I remember nurses saying, "Oh, you're making it harder for me tonight because your hemorrhaging is increasing." They would be joking about it. I am a serious soul about things like that and I would not do that to another person. And so I took it upon myself to say, "Give me a break, I'm just going along for the ride on this one" you know, trying to play their little games but trying to raise their damn consciousness level.

Beth's conclusion about the hospital as an institution and the high risk maternity ward in particular, was that neither treated women well.

> I've seen women who complain and do a lot of that stuff but it's horrendous what psychologically happens to them. I have absolutely no positive feelings for .... Hospital, Ward .... What they put women through in that institution was horrendous.

Provision of information by NICU medical staff. A number of parents found it difficult to obtain sufficient, comprehensible information from medical staff, and presented a variety of explanations for this situation.

> Philip: Unfortunately, technically during the time before Martin was born, I think we got involved with what I would consider the normal stance of the medical profession and that's "We'll not reveal very much at all."
>
> Noel: They don't really tell you too much ... 'cause then they figure you get high hopes.

Although appreciating that doctors had busy schedules, some parents nevertheless felt resentful that their need for clear information about their babies was not being met. Yet even as they expressed this resentment, parents downplayed their right to require that doctors allocate time to discuss their babies' conditions with them.

> Res: Did you find when doctors gave you information that it was clear to you, that you could understand it?
>
> Barb: No, they never do. No, they don't have the time ... [The neonatologist] spent 15-20 minutes.
>
> Noel: Ya, 20 minutes. 'Cause they've got to make rounds, they usually don't have time.

Will: The doctors are so fly by night. You want to go out and down the corridor one day when they're taking off their gowns ... you know, you didn't get no information. No, I never really spent any time talking with doctors.

Res: Did it bother you that you couldn't have access to doctors?

Will: No, because they're specialists and they don't have too much time for small talk. If they have any ... information, they pass it on to the nurses.

A mother interviewed by Perlman (1986) personifies the ambivalence felt by parents seeking information about their infants from doctors.

> You realize that it really is your baby, and within reason you have the right to ask any question you like.. You want to know about your baby, you want to ask questions, silly things sometimes - why is she doing this? - but you feel you are wasting somebody's time.

It was frustrating to Barb that the neonatologists chose to spend their limited time with her in an environment unconducive to satisfying discussion.

> The thing I didn't like ... was they would talk to you ... there [in the NICU] ... with all the buzzers and machines going off and how can you concentrate on asking questions .... You're talking to your doctor and a child is being admitted and there's 10 people coming running to him for everything.

A parent's state of extreme fear at times hindered doctor-parent communication. Pam's reaction to an item of bad news about Corey's condition, was one of all-pervading apprehension that interfered with her ability to hear and think calmly.

> Kevin: Well, you [Pam] had phoned the doctor and he said something to you, then I had to phone the doctor back cos I didn't think you'd got it right. When Pam talked to them, they'd say one thing was going wrong and she would not hear anything after that and she'd panic and then I'd have to phone them back and ask what's going on.

Pam's continuous state of apprehension about Corey's grave illness may have been at the root of her suspicion that staff were not revealing all the facts to her.

> I guess I did think they were keeping something from me ... like, "Something's going to happen to [Corey] ... something's wrong, you're not telling me everything."

Kennell and Klaus (1982) have observed a similar state of suspicion in a number of mothers of premature infants. The mothers' wariness is possibly a reflection of their state of extreme distress in which they find it difficult to remain objective while the possibility of their babies' deaths is always at the back of their minds. This can be a difficult situation for staff to deal with but knowing the dynamics underlying the mothers' behaviour is a basis on which staff can plan their responses to the women involved.

> Philip: We were definitely exceptional from the point of view of wanting to know medically what was going on and also challenging the prognosis and diagnosis.

Provision of information by NICU nurses. Noel and Barb found nurses to be more satisfying sources of information about Annette's condition than were doctors.

> Noel: I think you get more out of the nurses.

> Barb: I think they volunteered more information before you asked them questions. You know, they'd sit down and say, "Well, this and this has happened today."

Several parents became confused and upset when they received differing accounts of their babies' condition from individual nurses. The discrepancies puzzled Will who decided the best he could do was choose whichever explanation sounded most rational to him.

> Well, you ask five or six different nurses at different times the same question and you get different answers. I don't know why each one would have a different answer. So you have to use kind of your own commonsense, especially if it's on a commonsense question.

When Janet received seemingly incomplete reports from nurses on different shifts regarding Denise's progress on a particular day, the lack of a consistent picture engendered feelings of unease in her. She realized that in her present state of insecurity, she needed the security of consistent, accurate information from the professionals to whom she had entrusted Denise.

> Whenever we talked to a different person, we always got a different answer, and with me particularly, I didn't need to hear that. I needed to hear the same thing over and over again, and that was making me really tense and nervous. You would say, "How is she?" and the nurse would say, "Fine." Then you'd ask the other nurse and she'd say, "She had some brads today." And I'd think, "How come the other one didn't tell me that?" Or one would say, "Oh she had a blood transfusion today." and the one during the day didn't tell you that.

Kevin and Pam found it unsettling when two nurses provided contradictory reports about Corey's physical problems.

> Kevin: You'd talk to one nurse and they'd say one thing and you'd talk later to another and they'd say, "Well, here is this that was wrong before" and there wasn't anything like that ... And we got confused for a while.

On the whole, however, Kevin had been pleased with the helpfulness of both doctors and nurses.

> Any of the nurses and doctors would sit down and answer any questions we had... The nurses were really good about that. If they were doing something, they'd explain what they were doing and why.

To Beth, it was inevitable that she and Philip would receive differing reports about Martin from nursing staff, given the large number of nurses working in the NICU and the fact that each of them would experience Martin in her or his unique way.

> Because there were 146 different nurses working on him at any given point in time, there would always be different perceptions of Martin.

The figure quoted by Beth is comparable to that furnished by Minde et al. (1980) who stated that 150 nurses were working in the NICU of The Hospital for Sick Children in Toronto at the time. Minde et al. (1975) state that babies in the NICU could be cared for by as many as 70 nurses in a period of 7 weeks.

The employment of large numbers of parttime nurses in NICU's and parents' resulting problem of reconciling reports from various nurses, has been noted by Kennell and Klaus (1982). They comment that parents telephoning the NICU may experience confusion when, for instance, several nurses report on their infants' condition within a period of several hours, with each nurse using slightly different terminology.

It was Beth's opinion that the large number of nurses working with Martin was a factor which led one nurse to make a written assessment of Philip's relationship with Martin that caused emotional pain to both Philip and herself.

> Philip: We'd go and visit at night ... when the nurses would go on breaks. And then [we] started reading the ... doctors' and nurses' notes. One night I found all the notes that were written on us and the thing that bothered me the very most was that it was an observation with a conclusion: "Dad came tonight. He seems very reluctant to want to touch baby. There seems to be a problem with bonding." .... I didn't want to touch Martin that particular night ... because his skin looked very sore and I didn't think I should be touching him because I see him touched so much by the nurses. I just wanted to be with him. And so the conclusion she had drawn was totally wrong ... It really upset me.
>
> Beth: It really, really hurt. And so I remember saying at the tail-end of one of the meetings [with NICU staff] ... that there was a perception that was not correct and it really hurt me that someone had made it .... It was OK though, they immediately acknowledged it.
>
> Philip: I think that by bringing it to the surface, I believe they had seen the error of their ways.
>
> Beth: Well, you know .... in the NICU there's 146 different nurses. So they were really going off at a tangent.

At times, Kevin and Pam experienced difficulty in obtaining from some nurses the detailed technical information they were seeking, and

Kevin wondered if this problem might arise from the nurses' belief that the information was beyond the grasp of Pam and himself.

> Whoever was responsible for him when you phoned, would come and give you the information. Some would come right on and go through everything ... and some you'd have to pull the information out of them, like "How is he?" "Well, he's fine"... There were certain things like blood gasses we were looking for that we wanted to know what the level was. Maybe they thought we didn't know what the numbers meant .. but we did.

In what appears to be the only effort so far to study in depth the communication between parents of VLBW premature infants and the NICU staff, Perlman (1986) interviewed parents at The Hospital for Sick Children in Toronto. Her analysis shows that as infants' stays lengthened, parents' questions moved from those seeking general information to those requesting more and more specific information, for example, the readings of monitors and respirators.

Nurses and junior medical staff complained that parents' concentration on detail was interfering with the development of their relationships with their infants. One neonatologist surmised that the parents' desire for in-depth information was a way of avoiding issues connected with the problematic survival of their babies. Perlman (1986) found, however, that providing parents with detailed information about the various types of treatment their babies were receiving, proved valuable in facilitating parents' attachment to their infants. A possible reason for this effect may be that as parents became more knowledgeable about the purposes and functioning of the equipment, they became more comfortable in its presence and so were able to be more relaxed with their infants. In addition, as they understood the various readings more clearly, they could see when improvement or regression had occurred in their babies and could modify their interaction with them accordingly.

Philip and Beth were more fortunate than the other parents in the matter of obtaining the information they desired from nurses, because a nurse offered to act as a primary nurse to Martin. As such, her duties typically included concentration on that infant while she was on duty, planning his immediate future care with doctors, coordinating his care with nurses on other shifts, and acting as the focal nurse with whom his parents could discuss his condition (Aradine, Shapiro & Uman, 1980).

Philip was disappointed that the NICU supervisors were unable to find enough nurses willing to act as Martin's primary nurses so that he could receive 24-hour care from them. Nevertheless, he was well satisfied with the rewards he was accruing from the participation of Beth and himself in the primary nurse arrangement, particularly with regard to their relationship with one of the two primary nurses caring for Martin.

> This one particular nurse expressed an interest in Martin and asked to be our primary nurse. And it was just great, it was really super. And we had another primary nurse that came in and they tried to get a third. Unfortunately, both of the primary nurses ... were on a parttime basis.

The need of Beth and Philip to have one accessible professional fully knowledgeable about their baby, has been felt by other parents. A mother interviewed by Perlman (1986) commented:

> I must say that the nurses in the nursery tried to give me the feeling that "We understand, this is your baby, you want to know her." But you know, they change and it is nice to talk to the person in charge.

Depersonalization in the NICU. Some parents came to believe that the never-ending flow of infant patients through the NICU had caused the staff to overlook the fact that each patient was a distinct and unique person.

Pam found it disturbing that a nurse repeatedly referred to Corey as a girl, with the possible implications of either mistaken identity or lack of interest in the sexual identity of patients.

> I'd phone up and you have to give your ID number, then a nurse would come on and say everything about your baby. A couple of times this one nurse said, "Well, she's doing fine." Well, my baby's not a girl, so I'm thinking, "She doesn't even know my baby's a boy."

Several parents interviewed by Lissenden (1984) were perturbed by the depersonalization of their infants expressed in the terminology NICU staff used when referring to patients. One parent felt it was more bearable to have her infant assigned the incorrect sex than for staff to refer to her as of a neuter gender.

> I know it's hard to remember the baby's name when there are so many but somehow a wrong sex is better than "it."

Barb resented the implication in nurses' generalized statements that all infants were the same, thereby denying Annette's identity as a distinctive individual.

> [Information] was always second-hand: the nurses' experience, "This has happened before to a child, this is happening to your child", you know. Every child is different.

Barb was particularly incensed when on one occasion, a doctor confused Annette with another patient.

> When she got sick in the hospital, "She wasn't sick" said the doctor, oh no. The one doctor that was talking, [was] talking about a totally different child.

Noel believed several factors could have caused the doctor to make a mistake.

> Well, they get so many patients and that.

Like the parents in this study, parents of VLBW premature infants participating in a parent support group at the University of Oregon Medical School, stated that it was important for them to know that each of their infants was perceived and treated as a separate, unique person, rather than being viewed by NICU staff as "just another sick baby" (Duhamel et al., 1974, p. 1055).

In addition to certain staff members' seemingly impersonal treatment of infants, some parents also encountered depersonalization of themselves and other parents as a result of institutionalized values and practices within the hospitals where their babies were being treated.

Included among these experiences, were those of a couple and their infant who had to be rehospitalized for surgery.

Philip was critical of certain values he discerned behind the behaviour of medical professionals, and to a lesser extent, that of nursing professionals. Firstly, he believed that it was the general practice of staff in institutions to judge the worth of members of the public by their physical appearance. More specifically, it had been his experience within the NICU that the amount of respect he was accorded by medical staff and some nursing staff, was influenced by his adherence or non-adherence to the formal style of dress traditionally favoured by the medical profession.

> Whenever you go into an institution ... your physical appearance is most predominant. You are immediately assessed on that physical appearance. The respect and the conversation level or whatever I would get when I went in wearing my business suit by doctors in particular, and nurses at a lesser degree ... I was talking to them on a different level than if I went in wearing my sweat shirt and jeans. And I made it a specific point when we had meetings with the doctors ... that no matter what ... I would make a point of complying with their need to have myself dressed in a suit.

Philip believed that the pressure from medical professionals for the public to conform to their values, arose from a sense of elitism which had been inculcated in them during their training.

> I heard ... so many times at the hospital, you know, "We're professionals here" and that's always been drummed into them. And that's part of their etiquette, you know, you're on their ground. If you want to stick handle with them, you play by their rules. And they can relate to you far better in a business suit and a few technical terms.

Philip's belief that doctors' socialization into their roles includes preference for patients who share their ease with formal attire and medical terminology, is borne out by research on doctor/patient interaction. It has been found that doctors do not expect and even discourage questions from working class patients but expect questions from, and supply more information overall, to patients of social status closer to their own, and who are more at ease with medical jargon than are most skilled and unskilled workers (Calhoun et al., 1976).

Beth and Philip were troubled by a second facet of depersonalization of parents which appeared to be based on some professionals' negative views of people with different social backgrounds to their own. Beth and Philip saw this negativity expressed in what they perceived as discriminatory and authoritarian treatment of members of specific age and ethnic groups.

> Philip: I don't know ... but it must be a fairly high percentage of children that have been brought in from remote areas and in particular, either Eskimos or Indians. And there's a tremendous number of first mothers that are very young .... There was a lot of people that we saw that were not ... treated fairly, they were just not given the credit due to them or whatever. They were treated like children.
>
> Beth: It was appalling, it made me really mad at them. How dare they take those kinds of assumptions and use them against people? Terrible power trip, especially in a situation like that, and that happened often.

Barb, Noel and Annette experienced depersonalization as a family when Annette was readmitted to hospital for removal of a cyst. The treatment all three of them received led Barb to conclude that the hospital as an institution had no concern for the welfare of child patients and their parents.

As requested, Barb and Noel brought Annette to the hospital on a Sunday and sat with her through the night. Because Annette's surgery had been scheduled for the late morning, Barb had to spend several hours trying to pacify an infant bewildered by the sudden change in her accustomed feeding routine.

> They scheduled her at a quarter after 11 .... on the Monday .... and finally took her at noon .... She was up at 6 o'clock that morning .... She couldn't have anything to eat after 2 o'clock that morning .... Try to tell a kid who can't understand that she can't have a bottle or she can't eat.

When Barb described to a doctor the upset Annette had experienced, he stated that it was established practice to schedule surgery on the more seriously ill patients to take place first each day.

The lack of facilities, the overcrowding and the understaffing on the children's ward outraged Barb, both because she and Noel suffered as a result, and because the conditions were unfair to the patients and to the overworked staff.

> You can't do this, the playroom is closed, you can't go out in the halls .... (There was) one nurse for all those kids... There's three kids in one little closet. All the parents were there. You can't breathe in there, you can't sit in there.

> It's just terrible. I stayed overnight there and I couldn't even sleep in the same room that Annette was in because there was a father there staying with his daughter. It was a nightmare for us, those 3 days .... I'll never be caught dead there.

Whatever the reasons for the actions of individual staff members and for the institutional policies and practices whose impact parents experienced, the result for them was a further increment in the already heavy burden of stress with which they were having to cope.

Parents' personal encounters with NICU staff. Although parents found much to praise in the NICU staff's performance of their duties, mothers in particular were disappointed and often distressed by the behaviour of some staff members toward them at times when they felt most in need of support.

It was Janet's experience that many nurses were competent in the medical sphere but lacking the ability to treat upset parents with sensitivity.

> They weren't always all that tactful .... some of those nurses ... should have been working individually with the babies maybe but not dealing with the parents. One time I came in there ... and I was still crying and the nurse said, "What's the matter with you?" She was really quite rude. And I said, "Just leave me alone, you don't know what I'm going through, just leave me alone."

Pam had a particularly disturbing interaction with a nurse during the period when Corey was critically ill. She had had him baptized and the nurse without first discussing the action with Pam, accused her of abandoning any hope for Corey's recovery.

> The nurse said, "Well, you're writing him off" and I said, "I'm not writing him off." "Well, you had him baptized." I said, "I feel I have to do this but I have never written him off." I was scared, very very scared. I had him baptized because I was brought up that way ... I would probably have felt very guilty if something had happened to him and I didn't.

In contrast to the incidents involving Janet and Pam, Philip and Beth were unsettled by what staff left unsaid during one of their regular meetings with NICU staff.

> Philip: At ... one of the meetings, somebody ... said, "Well you know, there's a tremendously high rate of separations due to stress." And that's all they said. And that played on ... my mind as to "When are we going to separate?"
>
> Beth: It must be going to happen if everyone says it's going to happen.
>
> Philip: So ... we were worried about it.

NICU staff meetings can be opportunities for staff to discuss personal problems that appear to them to be affecting parents' ability to cope with the situations they are currently experiencing (Kennell & Klaus, 1982). However, staff do a disservice to parents if they merely hint at the problem when meeting with them, as in the case of Philip and Beth, instead of addressing it directly. The outcome of the incident involving Beth and Philip, was that they were left feeling others had more insight into their relationship than they did, and the staff were left in ignorance as to the actual status of that relationship.

The issue of breastfeeding became a painful one for four of the five mothers who were unable to breastfeed for various reasons. Like other mothers of VLBW premature infants (Lissenden, 1984), the four mothers believed in the benefit to their babies of breastfeeding and would have liked to do so for at least the first postpartal weeks. Pam, like other mothers (Newman, 1980), cherished breastfeeding as a unique attribute of mothers.

> It's the only thing that you can do. Nobody else can do that for your baby but you.

The one mother who decided against breastfeeding from the outset and the other three mothers who tried and then terminated their efforts, all felt guilty because of what they experienced as either the judgmental stance of some staff or because of staff pressure, both covert and overt, for mothers to breastfeed as long as possible.

Barb appreciated the support of sympathetic nurses when she found others disapproved of her decision not to breastfeed because of her return to work one week after her discharge from hospital.

> Some of the nurses didn't think too highly of me but more were acceptable [sic]. There was really just one that made me feel really guilty ... I talked to the nurses and they said, "Just ignore her."

Both Beth and Janet sensed a belief among members of staff that mothers who did not breastfeed were failing to fulfil their responsibilities. Beth persevered in her attempts to provide breast milk despite her lack of strength following Martin's birth, but the many demands on her energy after her return home, affected her milk supply despite advice from the senior nurse. Her feelings of inadequacy were intensified when she had to report her lack of success to the primary nurse and particularly when she finally had to tell her she was ending her attempts at breastfeeding.

> I was using a pump and I was very unsuccessful mainly because I was still very tired. And then when I got back [home] I became even more tired and the milk dwindled away. I spoke to [senior nurse] and she said, "Well, if you've got a toddler, put him on your breast." So I did and the milk came back again ... but it was just before Christmas and having to run to the hospital and prepare for Christmas and keep the household together, my milk dwindled again. And I remember the primary nurse saying, "Did you get any milk today?" And I'd say, "No, I didn't" and having to use milk from the milk bank... I was feeling very guilty about ... saying to Martin, "I will be there for you when you can nurse but I cannot keep the pace and feed Stephen [too]." It was just not possible [and] when you start primary nursing, you are exposing yourself by saying, "I can't do it, I can't do it and it's killing me to tell you this because it's killing me to have this thought myself." .... And I was always trying ... to keep this guilt from pouring all over me .... There was a tremendous amount of pressure ... There were certain expectations that weren't said: "A good mother breastfeeds in this day and age."

Janet felt most pressure to breastfeed from one of the doctors.

> If you don't breastfeed, I get the feeling it's going to mean it's not natural and you're copping out and I don't think it should be that way .... It wasn't so much the nurses, it was one of the doctors who felt I should breastfeed right away.

The nurse who was mothers' consultant on breastfeeding, sympathized with Pam regarding her unsuccessful attempts to pump milk for Corey over a period of 3 months under adverse conditions, and supported her decision to desist. She did not, however, inform other nurses of this fact. Pam was therefore exposed to intermittent requests for breast milk that contributed to her feelings of inadequacy as a mother.

> I was pumping and then when he got bad, it just stopped .... It hurt to pump my breasts at that time. Being so upset and going out there at all hours of the night and day, I wasn't doing it as much. I tried for I think a good 3 months afterwards and I didn't get anything .... The liaison nurse .... told me, "Give up, you've tried long enough." .... So sometimes I'd go in and there'd be a nurse who didn't know me and she'd say, "Do you have any breast milk for Corey?" I'd say, "No." I didn't want to explain to her but just her asking me, I felt incomplete.

There appeared to be a lack of understanding on the part of staff with regard to the impact on mothers' self-image of their inability to breastfeed successfully. Beth felt guilty because she was not a "good mother" while Pam felt she was lacking an important maternal attribute. Janet was even more self-critical, recalling that she felt "absolutely incompetent as a mother."

Over twenty years ago, Kaplan and Mason (1960) pointed out that considerable effort is required of mothers to successfully pump their breasts and then transport the milk to the hospital. Shosenberg (1980b), writing 20 years later, makes the same point, commenting that medical professionals are often unaware of the difficulties mothers face in providing breast milk. The lack of awareness among nurses was illustrated by the accounts of several mothers interviewed by Lissenden (1984). When they delivered to the hospital the small amounts of breast milk they had pumped with a good deal of effort, nurses asked, "Is that all?"

Lack of planned transition of infants' care from the NICU to community professionals. When infants were due for discharge from the NICU, there appeared to be no formal procedures for transferring their care from the NICU to community-based professionals. Beth and Philip were the parents who suffered the most from this lack of planning.

As soon as Martin became ill the day after arriving home, Philip and Beth commenced a hasty search for a paediatrician because the NICU neonatologists had not arranged with a paediatrician in the community to assume his care after his discharge. After requesting from the NICU staff the names of possible paediatricians, they contacted the doctor who had been suggested. Their initial experiences with him proved disillusioning and they consequently asked knowledgeable contacts for the names of other paediatricians they could approach. They were given the name of a paediatrician specializing in young children with respiratory problems, and he agreed to be Martin's doctor.

The NICU staff's lack of impetus in initiating a smooth transition of care for a child as ill as Martin, caused Philip to feel he had been abandoned by those he had come to trust.

> It's fine and dandy to have a really good, close relationship with parents while they're in your unit but you can't drop them like a lead balloon as soon as they're out of your sight ... And that's what happened to us. There was just no preparation.

American parents of a VLBW premature infant suffering, like Martin, from bronchopulmonary dysplasia, had experiences similar to those of Beth and Philip. In describing the problems of Robbie and his family, Aradine et al. (1980) report that Robbie's parents were dismayed to learn that the NICU staff had not seen it as their responsibility to assist them in planning for the future care of Robbie in the community. When they found a local paediatrician willing to generally monitor Robbie's condition, he chose not to meet with them or Robbie prior to his discharge. The authors comment that professionals did not seem to realize how anxiety provoking it was for Robbie's parents to see him leave the hospital where he had for so long received the care of experts, and know they would be largely responsible for his care once he was home, with the help of a paediatrician who had no knowledge of Robbie's past medical history.

In the Community Setting

With the exception of Sharon and Jim, parents felt the need for the services of professionals from the day they brought their babies home. Because Jim and Sharon were confident that Melissa would do well and because her progress was comparatively trouble-free, they felt no need for outside expertise to assist them in caring for her.

Nurses. Nurses played an important role in mothers' lives although not all the interactions between them were rewarding to mothers.

Public health home visitors Barb and Pam both welcomed visits from the public health home visitors. They found them to be conscientious on the one hand, but also found them lacking in knowledge about premature infants and the problems of parents of VLBW premature infants.

During one interview, Janet described the nurse who visited her as "really nice, friendly" but at another point, disappointment and anger surfaced in her criticism of the nurse's advocacy of breastfeeding. The nurse's views convinced Janet that she did not empathize with mothers who had difficulty breastfeeding and Janet therefore did not feel free to talk to her as openly as she had planned.

> Even though you tell them how you feel, you're still holding back how you really feel about certain things, about the way I felt about breastfeeding. Like I was feeling I didn't really enjoy it .... [but] she was very for breastfeeding: "Just keep on, persist." Just like the La Leche League ... if you're bleeding, if you're crawling, you can't walk, you've still got to breastfeed.

Apart from this difference of opinion, however, Janet found the home visitor a helpful source of information about problems she was having with other aspects of caring for Denise.

> There were times when I did phone her 'cause I wasn't sure and I didn't want to phone the doctor.

Public health clinic nurses Mothers paid regular visits to public health clinics in order that their babies might be innoculated against various diseases and to discuss their general progress with the staff.

Sharon found the nurses in the clinic she attended to be "very friendly" as did Barb who consulted them for medical advice.

> One time [Annette] had the flu and she had a really high temperature and they were really helpful. I'll phone the nurse before I'll phone the hospital.

Janet's visits to her local clinic were initially unpleasant for her because she experienced most of the nurses as unfriendly to herself and others. As a result, she discounted the staff as possible resource people to whom she could turn for guidance and information with regard to Denise's care.

> I won't depend on my clinic .... Every woman there ... except for one ... that makes a point of saying, "Hello, how are you doing, how's your baby?" - make you feel as if you're nothing but a mother who stays home: "I am working here, I've got a job." I'm a secretary ... and if I ever treated a person the way they treated me ... I'd be canned or reprimanded on the spot ... She [a nurse] yelled across the room at me ... When you see a child you smile, right? Well, they don't. I phoned and complained.

In a later interview, Janet reported: "I think everything is straightened out now."

Pam appreciated the perceptiveness and caring of the clinic staff with regard to the physical and emotional effects she was experiencing as she struggled to cope with Corey's feeding and sleeping problems. She was disappointed, however, at the staff's inability to provide her with information, or to guide her to sources of information on the subject of parenting a premature infant.

After Janet commenced work, Will had his first experience of taking Denise to the clinic for her periodic check-up and was impressed by the thoroughness and detailed questioning of the examining nurse. He also appreciated the straightforward, respectful manner in which she discussed Denise's progress with him.

> She was very good. She wasn't at all "smart", she was on the level.

Other nurses During the first few months after Denise's arrival home, Janet was so upset by her inability to deal with the feeding and crying problems that Denise had developed, that she frequently telephoned not only the paediatrician, but also his nurse who proved to be a valuable source of information and encouragement.

> The doctor's nurse, she's excellent. I phoned her once a day for quite a while.

Because of Martin's need for constant medical care throughout the day, Beth and Philip hired registered nurses to assist with the many tasks required to maintain his health and to monitor the items of equipment that supplied him with oxygen, humidified his air and suctioned secretions from his lungs. Because none of the nurses were either willing or able to make Martin's care their fulltime paid occupation, Philip and Beth had to hire and coordinate the shifts of numerous parttime nurses. This had become primarily Beth's responsibility and she had come to feel it as an onerous one.

> **Philip:** Our biggest problem is that there's too many nurses and we can't get a regular set of nurses that come on a continual basis.
>
> **Beth:** Ya, there's too many personalities. We have three major nurses that share hours .... and then we have ... relief people ... I'm reaching a point where I purposely leave them alone because I can't stand the constant interaction .... it exhausts me. We're looking at changes ... I would like ... to see if I can get one main nurse.

Medical professionals.

Parents' experiences with medical professionals Parents' accounts reveal that their experiences with medical professionals were sometimes positive and sometimes disillusioning. Parents appreciated finding competent and caring professionals but the treatment they received on occasion even from these professionals, left them feeling angry and at times, diminished as human beings.

Because of her own ill health and lack of confidence, Janet was in a constant state of anxiety during the first weeks after Denise's homecoming. The paediatrician was her main source of information and advice about Denise's problems and she overwhelmed him with telephone calls.

> During the first month and a half ... I was on the phone to my doctor four to five times a day. Everything to me was traumatic.

When one night Janet telephoned the paediatrician at home, he spoke to her in an abrupt manner and requested her to telephone him at his office the following day. His response left Janet feeling forsaken by the only person she had felt she could rely on for assistance, as well as distraught about the physical symptoms Denise had developed.

> I remember starting to cry and saying to Will, "If it wasn't important to me I wouldn't have bothered him ... She's not taking her food, she's vomiting, she's got blood in her stool." It was traumatic for me ... He phoned me the next day .... He said to me later, "Blood in the stool isn't always" - like he doesn't get excited about it. Of course, to me, I though she was going to die. But now he's got to know me.

The occasional impatient reaction of a busy doctor to the endless importunings of a frantic mother is understandable, but equally valid is the desperation she is feeling, faced with situations about which she has little knowledge and no previous experience.

The fact that Janet's paediatrician knew from past experience that blood in an infant's stool is not necessarily a sign of serious pathology, may have been one reason that he did not consider Janet's telephone call to him at home to have been warranted. However, his later comment seemed to indicate that he had failed to realize that Janet was not as knowledgeable as he was about the subject. This implication appears to have escaped Janet but after a similar experience, Pam felt as if she had been reproved for wasting the doctor's time with unnecessary concerns after she had contacted him about behaviours of Corey that were worrying her.

> I'm feeling silly afterwards as they say, "Well, they all go through this" but I don't know this, I never knew this.

Kevin echoed Pam's feelings of inadequacy as a parent needing to consult a busy doctor about matters that were not medically significant.

> You kind of feel silly, you shouldn't be bothering them with something so trivial ... but you have no one else to turn to.

On the whole, Pam was pleased with Corey's paediatrician, particularly because he answered fully any questions she put to him during appointments. She was also deeply appreciative of the gynecologist who had treated her for several years. Both she and Kevin had always had faith in his judgment and they felt events relating to Corey's conception and birth had justified that faith.

Beth and Philip had two encounters with the first paediatrician recommended to them, which were so unpleasant that they refused to retain him. The first instance related to the fact that he refused to make home visits despite the fact that he already knew about the various pieces of equipment Philip and Beth had to transport to his office to provide Martin with oxygen and other assistance during his visit. He had also apparently not taken into account the upheaval such visits caused in the family's functioning, with the care of the two older boys needing to be arranged as well.

The second incident involving the paediatrician occurred soon after Martin contracted a serious infection the day after arriving home. The paediatrician, who had visited Martin and other infants in the NICU 2 days previously, asked a question which implied that the fault for Martin's infection lay with Philip and Beth. His apparent lack of belief in their efficacy as parents convinced Beth he was not suited to be Martin's doctor.

> When we got there, Dr. .... looked at us and said, "What did you do to him?" So immediately I looked at him and I thought, "You're not the paediatrician I'd choose - to push responsibility [for Martin's infection] back on us."

Beth and Philip were relieved when the paediatrician they finally found agreed to visit Martin at home.

Although grateful to medical professionals for their knowledge and skills which had enabled Martin to live and to progress, Beth was troubled by what she perceived, as the derogatory attitudes of several of them toward mothers as a group. Like Philip, she believed and resented the fact that medical professionals treated lay people differentially according to the degree of formality of their attire. Nevertheless, after some initial resistance, she reluctantly decided she would have to compromise and dress more formally than she liked in order to establish her credibility with the professionals, and thus hopefully ensure that they would consider her ideas and opinions as a mother with more respect.

> I don't want to get into a game. It's never been a game to me until all of a sudden they were discrediting me 'cause I'm the mother and there's lots of connotations in "the mother" that I don't like. And so I tried to clean them up. I always used to wear the yellow things (hospital gowns) so that part of me was annihalated [sic]. I never have ... liked playing the game, it's kind of sickening to me ... And yet there is some validity in it and I'm starting to say, "OK. All right. I don't want you to discredit me because I am important in this." And it's a shame I have to do that, really it is.

Just as Janet was fortunate in eventually building rapport with Denise's paediatrician, so too Sharon was able to report her satisfaction with the paediatrician she was consulting. Discernible within her description of his good qualities, there appeared to be a suggestion that they were the antithesis of qualities she had encountered in other medical professionals.

> He's the kind you can go in and ask any question you want to. He doesn't look at you as if to say, "Boy, what a dumb question." He doesn't give you that kind of feeling.

Disagreements among professionals and para-professionals

Two of the three couples whose infants had to be rehospitalized, had to decide how to cope with situations in which they were faced with the opposing views of professionals and in the case of Philip and Beth, of para-professionals as well.

After Annette had had a cyst removed from her respiratory tract, the surgeon informed Barb that the cyst had proved to be benign and she therefore thought she could put the entire episode behind her. She accordingly felt both indignant and unsettled when she received contradictory information from the paediatrician attending Annette whose specialization was children's respiratory problems.

> [He] said, "Oh, we may have to bring her back to get ... the laser." I said, "I'll do no such thing." One tells you one thing and the other is thinking another thing. I think they should put themselves together before they start talking to the parents about what's what.

The severe, chronic nature of Martin's illness meant a large number of professionals and para-professionals were involved in his care. Apart from the registered nurses attended him daily at home, he was also receiving assistance from his paediatrician, the staff attached to the city's neonatal follow-up clinic, the staff of the pulmonary clinic operated by the hospital where he had been a patient, para-professionals from the hospital-based unit who assisted in the care of his tracheostomy and his support equipment, and surgeons and other specialists monitoring the status of his tracheal problems.

Philip and Beth were obliged to deal with recurring instances in which various personnel were offering them conflicting information and/or advice. This placed the onus on them to make difficult decisions which at times alarmed some of the professionals concerned, partly because they feared being blamed for any negative outcomes of the decisions.

> Beth: They [para-professionals] wanted [Martin] on Ventalin. And ... one of the nurses who had a fair amount of drug knowledge, said Ventalin is extremely hard on his heart ... When the doctors and [the para-professionals] caught sight [sic] of this, that we had taken it into our own hands, there was a great deal of power struggles. I had to say, "Look ... you aren't at our home and you don't know Martin ... If you want me to put it in writing, I will, to take responsibility." And that was their big fear: "You're going to blame me."

Beth and Philip were also sometimes required to weigh the opposing concerns of professionals. When Martin's paediatrician recommended that, because of Martin's susceptibility to infections, he be kept in isolation for a limited period immediately after his arrival home, a staff member at the neonatal follow-up clinic expressed apprehension about the effect of social isolation on Martin's psychosocial development. Beth and Philip chose to side with the paediatrician and to temporarily concentrate on expediting Martin's psychosocial progress through building a close relationship with him and encouraging his brothers to do so as well.

The fact that the many individuals and organizations working with Martin did not meet at regular intervals to share information and set joint goals for his treatment, caused Philip concern.

> They [para-professionals monitoring Martin's tracheostomy] come once a week ... but they don't consult with Dr. .... and they barely consult with Dr. ....

Beth was able to appreciate that the heavy workloads of the various professionals and para-professionals might make it difficult for them to remain in continuing consultation about a patient.

> Dr. .... and [the para-professionals] are fairly used up, they don't have much time ... So, it's hard.

At one point, when Beth and Philip felt themselves to be in the centre of conflicting and confusing advice and information from several professionals, Beth took the initiative in requesting a meeting to clarify the situation.

> I thought, "We're experiencing some disjointedness with Dr. .... and [para-professionals] and Dr. ...." and so I said, "I have a need that we all get together and express our expectations 'cause I'm not clear on them."

Summary

Parents sought accessibility and understanding in their relationships with professionals but were often disappointed. It was only during mothers' delivery experiences that these qualities were evidenced by most professionals on a continuing basis. Community professionals were generally more available than were hospital professionals, particularly in the case of doctors. However, some parents found certain community professionals deficient in comprehending parental needs.

The NICU's as institutions seemed oblivious of the importance to parents for staff to be regularly available to provide accurate and consistent information on infants' current status, and to convey that information at a time and in a location conducive to unhurried discussion. Heavy staff workloads and constant shift changes among large numbers of nurses affected the amount of time and the reliability of the information parents received from some staff members.

Parents often experienced a lack of understanding from professionals with regard firstly to the great emotional strain they were living under day after day, and secondly, with regard to the ignorance most of them felt about the characteristics and developmental paths of premature infants. Parents of an infant still ill on discharge, suffered even more. They were left to search virtually unaided for community based professionals who would assume the care of their babies and at times they had to deal with discrepant medical opinions.

The experiences of individual couples brought to light negative aspects of institutional values and practices. The welfare of patients and their parents seemed to be a minor consideration in the provision of facilities and staff on a particular paediatric ward. In one NICU, societally prevalent prejudices as well as possible personal biases were likely contributors to some staff members' insensitive treatment of parents in certain age, ethnic, social and gender categories.

The cumulative effect of various deficits in professionals' interactions with parents, conveyed a message that, in comparison with the technological challenges treating VLBW premature infants presented, parental needs for information and empathy were of secondary importance. Some parents had apparently internalized this message. They appeared to feel apologetic about their need to take up a busy paediatrician's time in their quest for general guidance and information about the care of their babies.

It would seem that the technology needed to save VLBW infants' lives has proven successful but policies relating to the optimal recruiting, training and deployment of staff have not yet sufficiently taken into account the personal needs of the parents whose infants have survived.

Theme 5: Support Networks - Sorely Needed, Often Inadequate

Introduction

Families are not units isolated from the rest of society. Their members interact with the institutions, groups and individuals who comprise that society. Formal and informal support offered by these sources play important roles in assisting family members when they experience highly stressful events (Unger & Powell, 1980), including the birth of a premature baby (Shosenberg & Lennox, 1985).

When a focal person is the recipient of the efforts of several supportive sources, that person is said to have a support network. Elaborating on this brief description, Walker, MacBride and Vachon (1977) define a support network as:

> That set of personal contacts through which the individual maintains his [sic] social identity and receives emotional support, material aid and services, information and new social contacts ... [It] may include relatives, friends, neighbours, fellow employees or professionals paid for their services (p.35).

Emotional support is described as, "Behaviour which assures an individual that his [sic] personal feelings are understood by others and considered normal in his [sic] situation."

The above definition requires comment on two points. Firstly, the mere dutiful performance of required tasks by professionals does not constitute support. Professionals can only be considered supportive when the manner in which they relate to those they are helping, conveys respect and authentic caring (Cobb, 1976). Secondly, the definition incorporates both informal and formal sources of support, the latter represented by the reference to paid professionals as supportive persons.

The literature on support networks does not yield discussion of the differences between formal and informal support (the latter is also referred to interchangeably as social support by most writers). Yet there appears to be a lack of consensus with regard to the components of the two types of support. Walker, et al. (1977) expressly exclude professionals from their discussion of social networks without offering reasons for doing so, while Wandersman, Wandersman and Kahn (1980) include parent support groups organized by professionals in the social support category. There is, in fact, only very limited mention of formal support in the literature and that is not of a detailed nature. For instance, Unger and Powell (1980) devote a certain amount of attention to formal support systems but only ~~in order~~ to compare the priority given to their utilization by those in various circumstances of need, with that afforded to informal sources of support.

For the purposes of the present study, support networks have two components. One component consists of services organized by paid professionals to offer parents various types of support. The second component consists of individual paid professionals who not only provide the expertise they are obliged to furnish, but whose words and actions are interpreted by parents as supportive.

Informal networks consist of individuals and groups other than those professional in origin, from whom parents receive emotional and practical support. There is a lack of agreement among researchers about the inclusion in social support networks of firstly, families and relatives, and secondly, of spouses (Mitchell & Trickett, 1980). For the sake of clarity, in this study, kinship group members, including both blood relatives and relatives by marriage, are presented as comprising a family network. All other non-professional persons offering support to parents are considered as comprising a social network. With regard to marital support, this is treated in the present study as a separate category both for reasons of clarity and because of its importance as a source of support. Marital support consists firstly of emotional comfort conveyed by a spouse's words and actions (emotional support) and secondly, of acts of practical assistance which spouses perform for each other (instrumental support).

Hospital-based Support Networks

Formal networks. Parents' formal support networks ranged in size from moderate to non-existent. Because parent support groups had only limited impact, parents welcomed supportive behaviours from staff members whenever they occurred.

Parent support groups For most parents, weekly meetings of a parent support group, instituted by NICU staff and conducted by a senior NICU nurse and a NICU social worker, were the only organized, continuous source of general information and emotional support within the hospital setting. Only in the case of Sharon and Jim did neither spouse attend meetings of a parents' group. They did not appear to feel the need to attend, possibly because they had believed from the outset that Melissa would live and develop normally. They therefore experienced less emotional distress while she was a patient in the NICU, than did the other parents. Even if Jim and Sharon had been willing to attend parent group meetings, the fact that they lived far from the hospital and that Sharon did not have daytime access to an automobile, would have prevented her from attending meetings which were held at noon. The timing of meetings would also have precluded Jim's attendance because it clashed with his hours of work.

The remaining four mothers began attending group meetings during the first postpartal weeks. The extent to which they benefited varied but three of them found the experience helpful even though they attended only a few times.

In assessing the benefits of her participation, Barb's comments were mainly positive but her ever-present pessimism about Annette's future intruded.

> It was just a thing that you could go and sort of (short laugh) go over some of what's built up, you know .... It's

> good to relate to someone who's gone through the same thing too .... I think we were all looking for reassurance: "Please tell me that my child is going to live." That's the way I felt.

Two other characteristics of the group which Barb appreciated was its small size and the fact that it consisted of mothers only, although she was unable to verbalize clearly why she was more comfortable with fathers absent.

Beth attended meetings of a similar group in the same hospital and stated that because the group was held at noon, it was impossible for fathers to attend. Although she welcomed the opportunity to meet with other mothers, she attended a few meetings at which neither of the facilitators was present, whereupon she assumed the facilitator's role. Although she had had training and experience in that capacity, she resented being in that role because she was deprived of her chance to recount her experiences to group members and to receive their supportive feedback.

In retrospect, Beth believed that the support that would have been most helpful to her at the time, would have been occasional parent group meetings as back up to individual counselling. She would have liked a counsellor to invite her to unburden herself with regard to the many stresses she was experiencing and to assist her in formulating ideas for handling her personal problems more effectively.

> I needed someone to say to me, "Well, how are you going with it? Tell me." [and] give me some ... honest guidelines. I needed someone to say, "Gee, you two aren't relating well. Is it affecting your marriage?" .... Looking back on it, it

> would have been helpful to have someone saying, "You know, I see you doing this. What does it mean? Tell me, let me know."

Pam attended "one or two" parent meetings which were held in the early evening. Her memory of one meeting was that it was "a really good meeting" because she heard other mothers recount some of the same fears and doubts that she had had.

Janet attended a parent group in the same hospital on two occasions. After describing to the group her perinatal experiences and the emotional turmoil they had aroused in her, she no longer felt burdened by the thoughts and feelings she had been carrying within her.

> You feel like a weight's been lifted off your shoulders .... [It] just made me feel so good to talk about it.

Janet limited her attendance to two meetings for two reasons. Firstly, she found that other parents' accounts were sufficient to provide her with the much needed reassurance that, compared to other babies, Denise's problems were only moderately serious. Janet's second reason for discontinuing her attendance at group meetings, was that she feared she might become too emotionally involved with other couples' problems at a time when she needed all her energy to deal with Denise's postnatal complications and her own postpartal illnesses.

Will was the only father to participate in parent group meetings and he was present for only one of them. He did not feel a personal need to attend them and did so to please Janet. Once there, however, he felt comforted that, in comparison with other babies, Denise's health problems were not as grave as he and Janet had thought. Yet his statement of relief was tinged with self-reproach, as if he had no right to feel the worry he was experiencing about Denise's condition.

> To be honest with you, I just went to find out what was going on. I wasn't too worked up as much as Janet ... so I more or less went along because Janet wanted me to go .... You go there and you feel you're in a bad state in regards to how Denise is doing, whatever ... Then you go and tell your story before the other people ... and then when you hear their situation ... you feel, jeez, here you are mouthing off about how bad your situation is, and yours is not even as bad as theirs.

A further reason for Will's reluctance to be a continuing member of the parents' groups, was his tendency to want to know people well and to feel convinced he could trust them before he was willing to reveal his feelings to them.

> I don't know ... I like - I don't like but I tend to gather stuff on the side - I have to feel really comfortable with a fellow in order to release how I feel about different things .... If I know ... what I say is going to be taken seriously ... I have to know ... if I can expect him to keep it to himself .... I'd probably be the last one to speak [in a group].

Kevin was only free to attend the parent support group on his day off because the meetings were held in the early evening when he was at work. On the one occasion when he had decided to attend a meeting with Pam, it was cancelled because of a snow storm.

Even if a parents' group had met at a time convenient to him, Noel doubted whether he would have attended. He saw his sole need to be that of accurate information about his baby's condition, whereas he saw the purpose of the weekly parent group to be psychotherapeutic.

> I don't know if I'd get anything out of it. You see, I learned most everything about her from the doctors up there or the nurses on the ward. I don't know that they can really help fathers with a group therapy thing.

Philip also did not believe he would have participated in a parent support group but his reasons differed from those presented by Noel. He did not think he would have found membership in such a group personally beneficial because none of the other parents had had an infant who had been in the NICU as long as Martin or who was suffering as seriously as him from the same lung condition.

> I don't think I needed the moral support of having someone else in the same situation 'cause there wasn't too many situations the same [as ours]. There weren't any couples during the time we were there that had situations that related the same.

A further reason for Philip's reluctance to participate in a group, was his lack of certainty concerning the most tactful approach to use in talking to grieving parents.

> I didn't feel very positive in talking to other parents because you never really know what to talk to them about. You didn't know first of all, what their feelings were and didn't want to get into it cos you're sort of treading on thin ice ... If your child's doing well and theirs isn't, then it's a very, very difficult situation to be in.

Philip had come to the realization that the most helpful form of support for him would have been to develop a close relationship with a group of primary nurses who would have acted as nurses to Martin and as both informants and supportive persons to himself.

There is no research to show the rates of fathers' participation in parent support groups, consequently it is impossible to know whether the low participation of fathers in the present study was typical or not. A few researchers have, however, reported the reactions of parents of both sexes who found parent group discussions to be a valuable source of information and emotional support. A mother who attended a group facilitated by Shosenberg (1980b) at The Hospital for Sick Children in Toronto, came to regard the meetings as her main source of emotional stability and reassurance during a period when she thought she was losing her sanity.

> At first I was OK and didn't see why anyone would want to come to a group. I understood everything about the baby and felt OK myself. But my next visit, I really collapsed and cried and cried when I saw the baby. It just hit me suddenly and hasn't left since. Now I can hardly wait until our next talk. When I'm home I'm sure I must be going crazy.

Other parents of VLBW premature infants who had attended parents' groups at the same hospital, expressed relief at being able to talk to one another about the many similar painful experiences they all had had to live through. Duhamel et al. (1984) received a number of positive comments on follow-up questionnaires that were sent to parents who had attended parent support groups the authors had helped to organize:

> I was afraid of her but after the group sessions I felt I could care for her properly.
>
> We learned more about this baby than we knew about any of our other children when we took them home from the hospital.

> Thank you for attempting to help a very bewildered and frightened group of parents.

Nurses Both Pam and Janet encountered individual nurses with whom they felt comfortable talking about their feelings. In Pam's case, the senior nurse was the staff member in question, while Janet was consoled by the physical gestures of compassion she received from a member of the nursing staff.

> She was just a really kind person ... She would always come and put her arm around me, you know. Just a very gentle person.

Two primary nurses, and one in particular, were Beth's main sources of both emotional support and information about Martin's day-by-day status. She appreciated having empathic nurses with special interest in Martin, but she also realized that her relationship with them at times necessitated discussion of her personal affairs, often a difficult undertaking for her.

There were times when Beth felt the need to express her feelings to the nurses, not always with positive outcomes. One such occasion occurred when she was feeling particularly distressed and unable to communicate satisfactorily with Philip. She therefore confided her feelings to one primary nurse. This nurse became concerned enough about the strained relationship between Beth and Philip, to inform the NICU social worker, without first consulting them, that she thought they needed marital counselling. When the matter was raised with them in a meeting with NICU staff, Beth and Philip expressed their annoyance at the arbitrary manner in which the staff as a whole had decided what was good for them.

> Beth: Then I realized, "Hey, hold on here, we do have some control on how much we want you to intervene in our private life.... We had to say to them, "We've had problems before this, we shall continue to have problems, I'm sure, but we choose to do something about it ourselves."

The emotional support fathers received from nurses was of a more general nature. Noel, Kevin and Will particularly appreciated the fact that the nursing staff made them feel welcome in a variety of ways when they visited their wives and their babies. Apart from the warmth of manner some nurses displayed to all three fathers, Will appreciated being offered beverages when he visited Janet during the first postpartal days, feeling tired from the demands on him to spend hours at the hospital while still maintaining the family home, building furniture for Denise's room, and looking after his own basic daily needs.

Social workers Two mothers reported receiving emotional support from a NICU social worker. When Beth met the NICU social worker for the first time, she was gratified to learn that her previous conception of a social worker's role as that of information provider only, was incomplete. She was impressed by the social worker's sensitivity and comforted by her offer to schedule a counselling session with her whenever she wished for one. Although Beth did not feel ready at the time to accept this offer, she felt reassured knowing that

that source of assistance was available, should she ever feel the need for it.

Janet received consolation when she accepted a social worker's invitation to discuss her emotional distress arising from her conviction that some action of hers had precipitated Denise's premature birth.

> One day I went in there and it was already a month and I just broke down and she [the social worker] told me to come to her room. And I felt that I did something wrong [to cause Denise's prematurity] ... The social worker told me ... that's how a lot of people feel .... She was very nice.

Other parents of VLBW premature infants have paid tribute to the helpfulness of NICU social workers. According to Lissenden (1984), those parents in her study who used the services of a NICU social worker, felt that she or he helped them. A couple interviewed by Philipp (1984) felt greatly relieved to hear the NICU social worker state that a baby's hospitalization could be hard on parents because this statement mirrored their own current experiences. The father further stated that the social worker had been the only member of the NICU staff to ask him about his feelings, and he had found her empathic enough to have considered requesting a counselling session with her.

General Janet and Will appreciated the fact that the staff expressed concern about Will's well-being during the time that he was visiting Janet in hospital.

> Janet: The social worker and even some of the nurses would always ask Will how he was doing ... They made a point of asking him and I think that's important.

Will: That's right.

Janet commented further that fathers' physical and emotional needs were often overlooked by the staff on maternity wards.

Philip and Beth remembered with appreciation the supportive relationships they had developed with a number of NICU staff during the year that Martin was a patient.

> Philip: Beth and my relationship ... specifically with a few of the nurses .... and definitely with a few neonatologists, was a special one .... more than just a straight doctor-patient, nurse-patient relationship.
>
> Beth: I built up lots of very special relationships with different people in the unit.

Informal networks. Only two mothers were fortunate enough to be offered emotional support from informal sources while they were hospitalized.

Janet formed friendships with three mothers whom she met on the high risk maternity ward, all of whom eventually delivered premature infants. She developed a strong enough relationship with two of the mothers to have continued to maintain contact with them by telephone since being discharged.

Pam was thankful for the understanding exhibited by the patient with whom she shared a room on the high risk maternity ward. Her roommate was a nurse who had delivered her first baby prematurely and as a precautionary measure, had been hospitalized during the final weeks of her second pregnancy.

> She could just see by my face there was something wrong as soon as I walked in ... She really helped me through a lot ... She completely understood what I was going through.

Like Pam, other hospitalized mothers have received support from mothers with previous histories of premature deliveries. Lissenden (1984) reports that several women who had shared hospital rooms with mothers who had previously given birth to premature infants, found that their roommate relationship enabled them to be mutually supportive before and after delivery.

Community-based Support Networks

Formal networks. Parents were not aware of organized sources of support in the community. Only two parents obtained supportive assistance from individual professionals.

Parent support groups Unlike the in-hospital situation, none of the parents attended a parent support group after their infants had come home. Some parents felt uncertain as to whether the NICU groups they had attended were only meant for parents with hospitalized infants or for parents with discharged infants as well. Several parents felt their time and energy were fully extended just coping with the care of their babies, other children and work responsibilities both within and outside the home.

Pam was the only parent who expressed a wish to attend a parent support group in which parents' problems and experiences during the first post-discharge months would be discussed. Other mothers have wished in retrospect that they could have attended such groups. A number of the mothers of premature infants interviewed by Brown (1983) believed they would have benefited from meeting with other mothers in the post-discharge period to share information and give and receive support.

Nurses Pam and Beth obtained various forms of support from nurses. In Pam's case, her experience consisted of a single occasion in which she visited the public health clinic with Corey and the nurses, observing that she was emotionally overwrought, suggested she consider joining a parent support group.

Beth received longer term support from some of the registered nurses she and Philip employed to assist with Martin's daytime care. One nurse became aware that Beth needed help with the household tasks necessary to maintain a large home housing two adults and three young children. She therefore used time when Martin was not in need of attention, to perform home maintenance duties for Beth, releasing her to be with John and Stephen. These occasions helped to lessen Beth's feelings of guilt about the inadequate amount of time she was usually able to devote to the two boys.

A second nurse, realizing how tiring Beth found her continuous daily interaction with the numerous parttime nurses working with Martin, encouraged her to go out and offered to take charge during her absence. Beth was grateful for this gesture, feeling a sense of release at being able to leave home and spend time in a different environment while knowing her children and home were in responsible hands.

Yet another nurse had come to be Beth's main source of emotional support since Martin's arrival home. She was a staff member in the neonatal follow-up clinic and they had met when Beth had taken Martin for his initial examinations by the clinic staff. She had felt comfortable enough in subsequent meetings with the nurse, to have commenced discussing personal problems with her.

Informal networks. Most parents individually possessed at least one informal support network that was sparse in size and/or supportiveness. As couples, they had access to pooled support networks but even these failed at times to provide them with the emotional and practical support they needed. Couples all had family networks (including grandparents, siblings and other relatives) and social networks (including friends, neighbours, co-workers and acquaintances). Only one couple appeared to receive adequate support from members of both their family networks and their social networks. They were also the only couple to enjoy regular, affectionate contact with both sets of grandparents.

Grandparents

Sharon and Jim Both Jim and Sharon were in the happy situation of enjoying good relationships with their own and each other's parents and of living close to one set of parents and in reasonable driving distance of the other.

Sharon's parents lived a short drive away. Although they were initially upset by Melissa's extreme prematurity, they did not discuss their thoughts and feelings with Sharon, leaving her to rely on her own interpretations of their few words and their facial expressions.

> They did not know what to think really, she was so small and stuff ... They just thought it was like real sad .... They didn't really say too much in front of me but I could tell by the way they looked that they were worried what was going to happen.

Sharon's parents regularly visited Melissa in hospital and after she came home. Sharon felt they were still currently very supportive. There was frequent reciprocal visiting and her parents provided child care whenever necessary.

Jim was born in a town about 2 hours' drive from his present home. His parents still lived in the town but they drove to the home of Sharon's parents immediately on learning of Sharon's admission to hospital. Jim was touched by this act of family concern and seemingly consoled by his father's matter-of-fact acceptance of Melissa's tininess.

> I phoned Sharon's parents from the hospital and Sharon's parents phoned my parents and they were in the city in 1.1/2-2 hours. They're very caring.
>
> Res: What was their comment when they saw her?
>
> Jim: How small she was. My dad always said as long as she's got toes and fingers, she's fine.

A possible reason for the understanding attitude of Jim's father may have been that he too had been born prematurely, a fact he revealed for the first time after Melissa's birth.

> Sharon: When Melissa was born, he said, "Ya, I was also only 3 pounds." and that was the first time we ever heard that. He'd never said nothing about that before.

After Melissa's arrival home, Sharon and Jim chose to consult their parents rather than professionals on the few occasions when they became worried about Melissa's health. The practice of initially seeking advice from one another with regard to health matters, rather than consulting doctors immediately, has become known as the lay referral system, and has been found to be common among members of close-knit networks (Freidson, 1960).

Barb and Noel In contrast to Jim and Sharon, Noel and Barb received little support of any kind from Barb's parents, the only living grandparents. Noel's father had died when he was a baby and his mother had died when he was 16 years old.

Like a number of other relatives and most friends, the approach of Barb's parents to newborn Annette was one of apprehensive wariness arising from their lack of knowledge about prematurity. Noel summed up the general reaction with seeming matter-of-factness.

> Leery, leery of her you know, because of - there was something really wrong with her .... A lot of people, they don't know, they've never dealt with a premature baby.

The responses of Barb's mother to Annette's prematurity appeared to be a mixture of fear of the unfamiliar and grief for the fullterm grandchild denied her.

> My mother was leery of her for the longest time. She was too scared, she's used to a big, bonny baby all the time .... My mom was very upset. She cried for 3 months about Annette's tininess.

Fifteen months after Annette's birth, Barb perceived her mother as still not completely accepting Annette as her grandchild. Four months later, she appeared to feel more comfortable interacting with her.

Reflecting on the possible reasons for her mother's uneasy relationship with Annette, Barb speculated that it was probably not due to Annette's smallness alone: "It was everything, all the complications." Whatever the reasons for her mother's emotional reactions, her continuing distress deprived Barb and Noel of support they needed, particularly during Annette's illness in the NICU and the trying first post-discharge weeks.

The response of Barb's father to Annette was one of withdrawal, which Barb had previously experienced as his characteristic approach to his relationships with others.

> He came up once to the hospital. He's like that with all his grandchildren ... It doesn't bother me, he's always been like that. He doesn't play no favourites one over the other, he's the same to all of us. He never says much.

Barb and her sisters had been born in Europe and she recalled that their home life in Canada had suffered because of their parents' preoccupation with working ceaselessly to achieve a comfortable life for them all. She and her parents had developed a closer relationship in recent years.

Pam and Kevin Kevin's widowed mother lived in the city and visited Corey soon after his birth. Her consternation and grief at his smallness and his frailty, were such that for many weeks she was unable to provide solace to Kevin during his anguish over Corey's struggle to live.

During the first months that Corey was at home, Kevin's mother was afraid to hold him but she proved a source of practical support on numerous occasions. She cared for Jill while Pam was in hospital, and did so again when Pam wished to spend several hours at a time with Corey in the NICU. She visited Kevin and Pam regularly, offering Pam helpful advice on such matters as suitable solid foods for Corey.

Pam had been born in a province at the opposite end of the country but had lived in Alberta for almost 11 years. Her parents still lived in the province of her birth. They were deeply involved with each other and maintained only tenuous contact with her. Her relationship with her father had been consistently fraught with tension but she had always felt close to her mother. Pam appeared to feel deeply hurt that her parents did not seem to care about the problems she was experiencing, nor about her wish to maintain contact with them, both as parents and as grandparents.

> I've invited them to come and see their grandchild but they've not come, they've made that choice .... They've got their own home ... and they like everybody to come down there ... and we just can't do that all the time .... I'm disappointed in my mum. I used to phone her all the time but I stopped because I can't afford to ... She was upset, "Well, I thought you'd phone me." I said, "Well, I told you I couldn't. I can't afford it anymore." She could at least call me, I thought, once in a while. She hasn't seen [Corey] and I can't see us going to them for maybe another 5, 6 years [and] I can't see my mom and dad coming her, so in 5 or 6 years I know my kids will be of an age and they won't have seen them.

Janet and Will Will's parents, like Pam's, also lived at the opposite end of the country and he and they maintained telephone contact. They were extremely worried when Will informed them of Janet's premature motherhood but delighted that he had become a father and provided them with a grandchild.

Janet's parents lived nearby. Her mother's health had deteriorated over the preceding 10 years and she had had difficulty accepting that there was no cure for a spinal problem she had developed. This problem had limited the scope of her daily activities, including her ability to pick up Denise, and she had become despondent. During the first 3 months after Denise's homecoming, Janet's mother was so preoccupied with her own problems that she could offer Janet little if any support of any kind. For her part, Janet acknowledged that during Denise's first weeks at home, she herself had been too immersed in her own problems to reach out to her mother.

> She's got bad arthritis in her spine ... I think she's starting to accept that that's the way it's going to be ... When she

> comes over, she's just happier when she sees Denise and I think that - you know, I feel closer to her than I did before because I didn't know how she felt. I knew she loved Denise but she didn't play and just didn't feel well and it was sort of my state of mind too, I wasn't really trying.

Janet also received minimal support from her father. He had retired unwillingly because of a back problem which had made it impossible for him to continue in his trade of automotive repair, which was also his only hobby. His enforced retirement had apparently induced such a deep sense of failure, that he vented his feelings on Janet and other family members.

> I think he hates himself so much for the way he is, that he tries to make other people miserable. So it's kind of a difficult situation.

Janet's parents visited regularly and every Sunday she, Will and Denise drove to their home for dinner. Janet's mother, sometimes accompanied by Janet's father, would care for Denise on some of the occasions when Will and Janet wished to spend time together away from home.

Beth and Philip Because Beth's parents spent less than half the year in Canada and Philip's parents no longer lived in Canada, Philip and Beth did not look to their two sets of parents for substantive emotional or practical support.

> Beth: My parents live here for 5 months of the year and for the remainder they go down to California. [They] aren't a support to us in that my mum's had a stroke so they're ... an emotional support when they're here ... As far as looking after the kids and stuff, it's like giving my dad another two sets

> of kids to look after and I've never done that .... when he went to the ICU, he would go every Sunday as a duty (laughs) - I don't know - as the grandfather you know.

Philip's parents had returned to England several years previously after spending many years in Canada. Although an only child, Philip did not have close, continuing communication with his parents. This was due to past disagreements with his parents regarding his choice of career, and to his father's withdrawal into heavy drinking.

> My background is an only child born in England, raised in Canada. We always had this big, big problem with my dad .... he's a confirmed alcoholic. They had high expectations of me ... be a doctor, or a lawyer, be very successful ... and if I didn't do that, then they were very disappointed.

Beth had sent Philip's parents a photograph of Martin while he was still a patient in the NICU but Philip's father had refused to look at it. He had previously intimated to Beth that he was repelled by people whose appearance or behaviour deviated markedly from the norm. Beth appeared understanding about her father-in-law's reluctance to accept his grandson because of his atypical appearance. However, it was important to her to rectify any misconceptions he might have about Martin and to continue her efforts to acquaint him with his grandson, if only by photograph.

> It's just his own insecurities that allowed that and I don't hold it against him. I will further send him a picture of his bright, blue-eyed boy that looks great (laughs), and try to heal whatever things he's conjured up in his mind.

Relatives, friends, neighbours and acquaintances

Barb and Noel Of the five couples in the present study, Barb and Noel appeared to have the least support from relatives, friends and neighbours. They received discouraging information and reactions from several friends and relatives following Annette's birth, conveying to Barb the most negative and fear-inducing connotations of prematurity.

> Barb: Some people used the word "abnormal" when talking about Annette. Some wanted to know if she had brain damage. We heard people didn't like to babysit preemies 'cause they were scared of emergencies.

Noel and Barb had regular personal contact with their adult siblings and their children. Some siblings lived in the same city as themselves, others lived in a nearby small city and yet others lived in a town within convenient driving distance. The only sibling too far away for regular personal contact was Noel's elder brother who lived in a town approximately 600 km away.

Noel appreciated the fact that three of his siblings visited Barb and Annette in hospital. That his oldest brother had refused to do so, conveyed to Noel a lack of caring about himself, his wife and their baby. This perception would have been exceptionally painful because this brother had acted as a surrogate father to Noel in his boyhood and adolescent years.

> My oldest brother .... I'd probably see him once a year, so - he didn't even go to the hospital. My other brother and two sisters went to the hospital, they were concerned.

Noel and Barb relied mainly on one of her sisters to provide child care when necessary. Barb, the youngest of four sisters, stated that they had always been close and often telephoned or visited one another.

Because they had been warned that it was hazardous for Annette to inhale tobacco smoke, Noel and Barb had requested visitors to their home not to smoke. Some of Noel's relatives had found this limitation unacceptable and had ceased to visit him and Barb. Noel seemed to view with fatalism this rebuff from family network members from whom he could justifiably have expected understanding.

> I have relatives - we don't allow people to smoke in our house. People get offended over that so they don't come and see me anymore. So that's the way it went.

On the whole, Barb and Noel had not experienced their friends as offering them a great deal of either emotional or practical support. Most of them were initially taken aback by Annette's smallness and by her initial illness, although they were later "surprised how she's doing now, compared to when she was first in the incubator" (Barb).

Noel and Barb had continued to receive negative reactions from their friends almost 18 months following Annette's arrival home. Barb appeared to feel hurt about the fact that many of their friends had ceased to visit them.

> I feel very disappointed in some friends of ours, they were friends ... A lot of times I just felt that because Annette was premature and that, things have changed. Nobody wants to be social with us anymore.

Noel: I think part of it .... It's the fact they can't smoke here.

Res: So are you saying to yourselves, "What kind of friends are they if that's the only reason?"

Both: Ya.

Barb had not yet felt willing or able to inform her friends of the emotional impact their neglect had had on her, nor had she asked them to furnish the reasons for ceasing their customary visits. She spoke of doing so at some future point: "One of these days I'll say something to somebody and then I'll find out first hand."

Mitchell and Trickett (1980) point out that many components of a person's personality influence whether or not that person effectively utilizes a social network. It is possible that Barb's personality may have been such that she found confrontation with her friends too difficult to attempt and so continued to wonder unhappily about the reasons for their abandonment of Noel and herself.

Kevin and Pam In their small family networks, Pam and Kevin found themselves engaging in both helpful and discouraging interactions with their few relatives.

Pam had one brother living in another province and a second brother who lived in a city a few hours' drive from her. During the early months of her pregnancy with Corey, she was confined to bed on medical advice. Her brother stayed with her for several days and cared for her during the hours when Kevin was at work. Pam and her brother continue to be in regular telephone contact and he visits her from time to time.

Kevin's relationship with his only sibling, a brother, had been a distant one during childhood and adolescence, but had improved somewhat in adulthood. His brother and sister-in-law lived nearby and were fairly frequent visitors. When Corey was born, they described him as resembling a bird, a remark which Pam, as the mother who had endured so much to deliver him, found both tactless and hurtful. Although the couple continued to visit Corey in hospital, it was never clear to Kevin what his brother thought and felt about Corey's premature birth.

Kevin and particularly Pam appeared to feel anger and frustration at criticism they received from Kevin's mother, brother and sister-in-law regarding their decision to have Corey discharged from hospital. It appeared to Kevin that the criticism ignored the validity of the reasons on which he and Pam had based their action. To Pam it appeared that Corey's welfare was not as important to Kevin's family as their wish to be publicly associated only with an infant relative whose appearance conformed more to the social norm than Corey's did when he arrived home.

> Kevin: Everybody's got advice which Pam doesn't like (laughs). Oh, we were crazy to bring him home - at first that was - and ... I don't know why they were all on the doctor for a while 'cause he said we might have to have [Corey] on a monitor when we

first brought him home: "You shouldn't bring him home."

Pam: "Doctor's crazy for letting you bring him home."

Res: Who is "they"?

Kevin: Oh, my brother and his wife.

Pam: His mom would say things. They'd rather see [Corey] there and not at home till he's 9 pounds and chubby and giggling. They'd rather see him like that. It was maybe a monitor, maybe oxygen. They said, "That's ridiculous, get another doctor."

Kevin: They couldn't understand that we wanted to have him home. He wasn't getting anything in the hospital that we couldn't give him at home.

The belittling remarks Pam and Kevin received from his family may have arisen from individual members' personal reactions to the stressful events surrounding Corey's birth and hospitalization. Shosenberg and Lennox (1985) point out that grandparents and in-laws may make negative comments for various reasons, such as their wish to be helpful or their need to lessen their own feelings of distress, but that whatever the reasons, the result is often discord between the couple and family members.

Pam and Kevin appeared to have a limited circle of friends, none of whom had had premature infants themselves. As a result, Pam felt bereft of supportive people who could understand the problems she was experiencing. She was able to receive a certain amount of support from a woman friend whom she consulted from time to time about various difficulties she was having in her care of Corey.

Kevin and Pam had lived in their present neighbourhood for 2 years but had not yet moved beyond the acquaintanceship stage with their neighbours. With Corey's improved health, they were contemplating a richer social life, and were planning to invite a group of neighbours to their home.

Beth and Philip As a couple, Philip and Beth suffered from a dearth of relatives and neighbours to call on for practical or emotional support. They were more fortunate with regard to friends and in Philip's case, his co-workers.

Beth was the youngest of three sisters. Her middle sister lived in a neighbouring province and her oldest sister lived within easy driving distance of Beth's home. She felt emotionally closer to her middle sister but only saw her when she visited the city briefly with her two young children each year. Beth's relationship with her older sister was not as satisfying and had carried undertones of conflict for most of their adult lives because of her sister's critical attitude.

> My oldest sister .... likes to tell me a lot about what I'm doing ... and it was only maybe in the last 5 years that she's kind of sat back and listened and said, "Oh, maybe she's got an idea that might work." So far as support goes, my older sister, no.

Beth respected her oldest sister's reasons for being unwilling to provide informal child care for Stephen and John, and appreciated her generosity in doing so in emergencies.

> As far as looking after the kids goes, no. She's got four of her own ... and I guess I just don't want to burden her

> anymore ... and she makes no bones about not wanting to go through anymore young children. And yet she's very good and in dire situations - when I was in hospital and we had nobody to help us - she would always say, "No problem."

Philip had no relatives to supplement the deficits in Beth's family network, consequently he and Beth valued the friends who formed their social network. Philip was accepting of the varied reactions to Martin that friends displayed when they visited him, and moved by the more sensitive responses.

> Their reactions have been anywhere from nonchalant, very inhibited approaches, to sheer amazement and very touched. I know a number of people that have gone in to see Martin and they came out in tears because they were so touched by his presence.

Philip also felt supported by friends' statements which acknowledged the demanding, complex task he and Beth faced in caring for Martin at home.

> I really don't think that I've talked to anyone that hasn't said - I guess it's standard to me now: "I don't know how you can do it, I couldn't."

Nevertheless, there were times when Philip felt lonely because he did not know any other parents who had a child with Martin's serious condition with whom he could talk about common problems.

Beth particularly appreciated the support she had received from members of a childbirth organization to which she and Philip belonged. They had assisted Philip and herself during the pregnancies and home births of John and Stephen, and did so again while she was hemorrhaging at home and while she was in hospital awaiting Martin's birth. She believed their emotional and informational support had been crucial in enabling her to weather the highly stressful weeks prior to her delivery.

> The midwife and .... all the people who had supported us during the last two pregnancies, they were the saviours for me, keeping myself together, because they would just come and talk and go through things.

Beth had deliberately limited her contact with friends even before Martin's birth. Because the roles of fulltime homemaker and mother made such demands on her time and energy, she had decided she would have to leave some of her social relationships in abeyance until her domestic responsibilities had decreased.

> I've let a lot of relationships go by the board the last 2 years. I just say, "Well, that'll be the test of our relationship." And I say to my friends, "My time is taken, I don't have time for outside commitments."

Philip's workplace proved to be a supportive environment for him and he was warmed by the caring attitudes of co-workers during Beth's hospitalization and during Martin's postnatal months. The support Philip received took the form of tactful enquiries, efforts to ease his workload and expressions of concern.

> I guess through the course of time with Beth being in the hospital, the word sort of got spread around ... typical reactions, sort of very evasive ... sort of ... went out of their way to try and help with little things rather than demand something ... I don't know, I'm just guessing .... And then when Martin was born ... I never really sort of let out, in fact I didn't even know how serious Martin was .... Then after talking to Dr. .... and Dr. .... I went back to work saying things are incredible but they're not

> totally ... impossible. So a lot of people ... always asked and were, you know, quite concerned.

Beth and Philip had lived in their present neighbourhood since they were children, and had seen it change in character as previous residents left and strangers moved in. They no longer felt at home and wished to sell their home and move to a neighbourhood more congenial to them.

> Beth: It's not a really friendly area as it was when we were growing up, so I haven't moved around too much.

Philip and Beth were fortunate in having a good relationship with a neighbour living on the same street, and they felt confident leaving John and Stephen in her daytime care during the 6 weeks that Beth was in hospital.

Janet and Will Janet was one of three children, all girls. She was close to a sister who lived nearby and they telephoned each other frequently. This sister was willing to care for Denise when asked to do so and had introduced Janet to a friend who also lived in the vicinity and who provided child care for Denise when no one else was available.

Will's parents, two older brothers and sister, as well as all his other relatives, still lived in the province of his birth, leaving him without a local family network to supplement that of Janet.

Will did not seem to have many friends, and described himself as a "loner" who was content with his own company. Janet had a circle of women friends of varying degrees of closeness. One of them was a mother whom she had met in hospital and who gave birth to a premature infant soon after she delivered Denise. She lived in a small town and she and Janet felt their friendship was important enough to maintain contact through long distance telephone calls.

Because most of Janet's other women friends had had fullterm babies, she felt unsupported and at times denigrated by them because they did not seem to understand that rearing VLBW premature infants often presented special problems for parents.

> Whenever I tell them something about Denise, because they've got fullterm babies, they figure that's the way you should be treating the preemies .... They almost make me feel ... stupid, or what you're doing is wrong ..... Like I've got one friend who says, "I think your doctor's full of hops, you shouldn't be putting your baby on cereal so fast."

Ill-informed remarks from significant others that compare the progress of VLBW premature infants with that of fullterm infants, has been a frequent enough experience of parents to have been noted by researchers such as McCarton (1986). She comments that these statements are in reality unkind acts, whether or not so intended. As such, they do not convey to parents the supportiveness they seek.

Sharon and Jim Sharon's four younger siblings lived with her parents a short drive away. She was in regular contact with them all and she was able to call on her thirteen-year-old brother to care for Melissa and Sean from time to time.

Jim was the middle sibling in a family of two daughters and three sons. One of his sisters lived abroad and his other three siblings lived out of town. This limited his personal contact with them but telephone calls and visits helped to sustain his relationship with them. They all drove to the hospital as soon as they heard of Sharon's impending delivery.

Friends of Sharon and Jim expressed disbelief at the smallness of newborn Melissa, varying in their ability to communicate their thoughts and feelings to her parents. It took several months for a close friend of Sharon to feel able to discuss her behaviour on first seeing Melissa, and on those subsequent occasions when she met Sharon. She explained that she had felt uncertain with regard to the appropriate way to act in a situation she had never encountered before.

> She knew it was small but she couldn't believe it. She said that to me later. She says, "Ya, when I seen Melissa, I didn't know what to say or what to do to you."

A couple who were good friends of Jim and Sharon, were also taken aback by Melissa's extreme prematurity but they felt more comfortable discussing the matter and they remained in continuing contact with both Melissa and her parents.

> Jim: They came right away [to the hospital] and they got to see the baby. Actually they were very good in caring. They're our close friends.

Jim felt himself fortunate to work in an environment where both his employer and his co-workers treated him considerately when he needed to take time off to deal with family affairs.

> I've worked there long enough so I know everybody ... They're really good and one fellow I work with, he's older, about 50, so I can talk to him just as I can talk to my dad. If you have any problems at home with the kids ... if I have to take a day off ... a week off ... with pay ... no problem. So they totally support you.

Sharon had come to know several neighbours and had struck up a friendship with a woman who lived on the same street and with whom she exchanged child care.

> My neighbour here and I get along real good. If anything ever happens, like I had to go with Melissa somewhere, she'll watch Seth and vice versa.

The extent of some parents' need for emotional support from family and friends, is revealed in their comments regarding the importance to them of having their experiences heard and understood by those close to them.

> Barb: It's hard to talk to people. After you've talked to your family, they sort of don't want to hear about it anymore. Well, I guess they do. You've like talked your way out.
>
> Pam: Too bad it's over with [the interviews] ... This is the first time we've ever had to be able to express our feelings to somebody.

Jaffe (1985) presents a possible societal factor contributing to the reluctance of even some intimate others to listen to accounts of stressful events. He comments, "In general, most people have a small tolerance for hearing about pain and struggle even in people whom they know personally. It's not something we allow people to talk about." Subjective reasons may also be behind this discomfort. Cadden (1966) proposes that people generally find it too discomfiting to talk to those experiencing severe stress, and may also be afraid of upsetting them by expressions of concern.

Marital Support

Introduction. During the course of their lives together, most couples experience a number of highly stressful events. It is a societal expectation that on these occasions, partners, by the very nature of their relationship, will provide significant support to each other. This expectation is implicitly shared by each partner. Marital support can be divided into two categories (Cobb, 1976). The first category, emotional support, refers to information conveyed in word and act, that one is loved and understood. Instrumental support, the second category, refers to the provision of goods and services.

Although marital support is only one of the factors that assist couples to cope with the problems of parenthood (Cobb, 1976; Leifer, 1977; Wandersman et al., 1980), its great importance to mothers has become clear (Selby et al., 1980; Wandersman et al., 1980). Most of the research emphasis to date has been on the efficacy of marital support for mothers. This is understandable given the fact that mothers bear the main burden of gestation, delivering and caring for children. Nevertheless, fathers are also in need of marital support while experiencing the exigencies of parenthood. Demands are placed on them to be particularly supportive of mothers during pregnancy and during the perinatal and postnatal periods. Furthermore, it has been suggested that the birth of a child entails a series of losses for fathers. The main loss is that of their partners' support because they, as the mothers of the new infants, themselves need extra support. Other paternal losses are said to include loss of sexual gratification, of financial stability, and a temporary loss of basic requirements of daily life such as sleep, food and recreation (Birdsong, 1981). It has also been proposed that childbirth can be almost as physically and emotionally draining for fathers as for mothers (Oakley, 1979).

A few studies have demonstrated fathers' need for emotional support under a variety of circumstances. In their study of couples' adjustment to first-time parenthood, Wandersman et al. (1980) found that this transition was facilitated most by a form of marital emotional support they refer to as marital cohesion, defined as "the sense of commitment and togetherness" (p. 339). This type of support engendered in fathers feelings of parental competence and experiencing of their lives as full and satisfying.

Some studies have dealt with the emotional impact on fathers of parenting atypical children. Fathers of retarded children experienced depression and felt inferior as fathers because of their role in procreating children of limited intellect (Cummings, 1976; Levine, 1966). Fathers of chronically ill children were also depressed and lacked a sense of parental competence, partly because they were not involved in daily activities that made them feel they were contributing to the welfare of their sick children (Cummings, 1976). The fathers of both the retarded and the chronically ill children appeared to be engaged in a long-term process of mourning the loss of their parental dreams for their handicapped children, and to be experiencing lowered self-esteem, anger and frustration as part of this process (Cummings, 1976).

Fathers of VLBW premature infants appear to experience negative emotions similar to those of the fathers just discussed. Although the emotional strain of being a parent of a VLBW premature infant appears to be less for fathers than for mothers (Jeffcoate et al., 1979; Yu et al., 1981), fathers nevertheless experience physical and emotional demands unique to their situation. These demands often commence while their wives are experiencing pregnancy problems and continue with the shock of learning that premature delivery will occur. Fathers frequently await their infants' births alone and in a state of extreme apprehension. Some fathers experience a sense of failure at having produced infants who are not healthy, attractive fullterms, with accompanying states of sadness and depression (Jeffcoate et al., 1979). Many fathers also feel anxious (Harper et al., 1976) and helpless (Philipp, 1984) during their babies' illnesses, and may worry as much as mothers about their infants' possible future developmental problems (Blake et al., 1975).

Existing findings indicate that when parents have delivered infants with handicaps, the related problems they subsequently experience may disrupt troubled marriages or enhance those that are already strong (Belsky, 1981). The extent to which parents of VLBW premature infants offer support to each other may be a factor influencing the degree to which their relationships are strained or strengthened by having their special babies. The preexisting quality of spousal relationships may be reflected in the amount and calibre of such support.

The relationships of the five couples in this study appeared to vary both in nature and in closeness. Because mothers experienced more stressful situations than did fathers, they needed more support, which was not always forthcoming. Mothers in turn appeared to offer adequate instrumental support but only limited emotional support to fathers.

Emotional support. As in the case of other parents who had had premature infants (Evans, 1985), there was often a clash of perceptions with regard to fathers' supportiveness of mothers. Fathers usually saw themselves as being emotionally supportive but mothers did not always perceive their behaviour in that light.

Sharon and Jim The need of this couple for marital emotional support appeared to be less than that of the other couples. There appeared to be several reasons for this situation. Firstly, they had felt optimistic about Melissa's survival from the moment of her birth, based on Sharon's intuitive feelings that their newborn daughter's life would not be seriously threatened by the sequelae of her extreme prematurity. Jim respected these intuitive promptings because they had previously proven correct in the case of Seth. He had been pronounced healthy at birth by doctors but Sharon had sensed that this was not so, and this was later found to be the case. Even if either child had died, Sharon and Jim stated they would have accepted that eventuality as God's will.

A second reason for the lesser need of Jim and Sharon for emotional support, was that Melissa's steady progress after her homecoming, meant that they were subjected to less worry about her health and future developmental outlook than were other parents with regard to their individual infants. Finally, Sharon and Jim appeared to require less emotional support from each other because both of them possessed family and social networks from whose members they received such support on a continuing basis.

Nevertheless, Jim's emotional support had been important to Sharon. When asked what she had most valued about having Jim with her during the experiences connected with Melissa's birth and the months since then, she replied, "Just being there." When invited to elaborate on this statement, Sharon had difficulty doing so, but agreed that in addition to the comfort of Jim's physical presence, his provision of verbal encouragement had been helpful to her.

Jim had provided a further demonstration of his sensitivity to Sharon's need for emotional support. On her discharge from hospital, he had taken leave from work in order to spend a week at home with her. Not only did this assist her in making a gradual return to her life as fulltime homemaker, but he was able to accompany her on daily visits to Melissa at a time when mutual support was valuable in helping each of them begin to learn to live in two worlds, their own accustomed one, and the new one of the NICU.

Both separately and in each other's presence, Jim and Sharon stated that theirs was a very good marriage. During interviews, their interaction and their statements appeared to confirm that theirs was a marriage with a solid basis of shared beliefs and mutual affection. They both belonged to a religious group which played an important role in their lives. They also shared a number of opinions on topics crucial to marital harmony, including the conviction that a happy family life was more important than material possessions, and that disciplining children was mainly a matter of firm but loving admonitions with spanking as a last resort. Sharon and Jim seldom interrupted each other and appeared relaxed in each other's presence. On only one occasion did they appear to feel anger toward each other.

Jim and Sharon agreed that the experience of having Melissa had had no significant effect on their marriage.

Jim: I think it's just the same.

Sharon: Ya.

Barb and Noel Noel had a more positive view than Barb regarding the impact on their relationship of having had Annette.

Noel: I think it brings you closer together as a family.

Barb: I don't know, it's hard to say. Sometimes I feel it brought us closer together, sometimes it made me more short tempered than I ever was.

Barb saw a beneficial aspect to Annette's arrival as the new family member, however. Her marriage had become for her predominantly an experience of predictable routines, and Annette's advent had given it a new and personally satisfying dimension.

> Before Annette we were already married 3 years ... The longer you're together, you know, things change ... When you don't have kids ... you do things together all the time. I was changed by having Annette. I don't know, it's been a good change, a break in your life from what you've been doing.

Barb's assessment of her marriage as a relationship she found only moderately rewarding, may have been the reason she evaluated it as average in quality. She did so in Noel's presence and he did not challenge her assessment. They both appeared to accept the modest quality of their relationship as satisfactory.

One factor that seemed to be maintaining their marriage at this level, was the lack of communication between them. Like other couples in the study, Noel and Barb did not appear to habitually discuss situations that were currently a source of discontent. An example concerned Noel's aversion to performing a specific caretaking task for Annette.

Barb: He won't wash her. I don't know why.

A further reason for the only moderate satisfaction Barb derived from her relationship with Noel, may have been the difficulty he sometimes experienced in detecting when she needed emotional support. For instance, he failed to sense the shattering effect on her of her doctor's refusal to encourage optimism about the possibility of Annette's survival.

> Barb: I told her [Annette] was doing real good and she said, "Don't get your hopes up." She wasn't very encouraging.
>
> Noel: Well, in a way you can't blame her. You have to expect the worst.
>
> Barb: Well, ya.
>
> Res: What would you have liked to have got from her?
>
> Barb: To be more encouraging. You know, there is hope, it's not all negative.

Noel provided emotional support to Barb in other ways. He visited her in hospital every evening during her one week stay there, and supported her reason for refraining from breastfeeding Annette.

She wanted to breastfeed but she was working.

In addition, although declaring he had never, like Barb, been driven to desperation at times by Annette's prolonged periods of crying, Noel expressed understanding that Barb's longer exposure to Annette's crying would have been more nerve-wracking than the briefer periods he spent with Annette on certain nights each week.

> Of course, mind you, Barb's with her a lot more than I am ... For the few hours I'm with her at night .... she's tired and wants to go to bed.

In reviewing the total experience of having Annette, Barb praised both Noel and herself for refusing to be overwhelmed by the many traumatic situations they had lived through.

> I thought we both did quite well, we didn't fall apart.

Noel and Barb appeared most relaxed with each other during the final interview and exchanged occasional affectionate glances. Their greater ease may have been due in part to their being interviewed in their own home. Their previous two interviews had been held in an office in a university building and particularly during the first meeting, they had both appeared ill at ease and had answered questions briefly. Their discomfort may have arisen from a number of causes and the interview process revealed one possibility. This related to the fact that they appeared inexperienced in reflecting on and analyzing behaviours and incidents. They seemed most comfortable when providing factual information and narrating events.

Janet and Will The relationship between Will and Janet emerged as an amalgam of dawning insights, sporadic appreciativeness, occasional empathy and inadequate communication of thoughts and feelings.

Janet showed most appreciation of Will's support in her comments concerning the period of her hospitalization. Will's presence was so valued a source of comfort to her at that time that she believed the experience had enhanced their relationship. Furthermore, his generally caring and responsible demeanour had exceeded her expectations.

> It was really important that he was there ... It brought us closer together and being that he just came through. He was just so good, unbelievable.

Statements by Will revealed his ability to empathize with Janet. He appeared sensitive to the fact that she had had to make adjustments in her life and face restrictions relating not only to being the mother of a premature infant, but to first-time parenthood.

> I can understand how she felt in the beginning because Denise is so small and her first baby ... But also the fact that she had a different lifestyle not being able to go to work and talk with the girls ... Now she's in four walls kinda like they're coming together on you ... Everything coming at the same time, it's had to be tough.

By the third interview, Will had experienced 6 weeks as a fulltime homemaker and had come to see the necessity for the wage-earning spouse to regularly assume child care responsibilities to free the homemaker to participate in outside activities.

The strain on their relationship in the months after Denise's homecoming, appeared to arise from Janet's physical, behavioural and emotional responses to the many stresses she was experiencing, and from Will's attempts to deal with those responses. During Denise's first 2 months at home, Janet felt so ill and depressed that she only possessed enough energy to cope with Denise's daily care. As a result, she was unable to invest effort in maintaining communication with Will and they grew apart for a period of time. Will acknowledged that they were having to work hard to firm up their relationship in those areas where it had weakened.

Their efforts were hampered at times by Janet's emotional reactions to the problems she was experiencing with regard to Denise's care and to her confinement to her home during a long, cold winter. Janet tended to vent her feelings of worry and irritability on Will and then to feel guilty for having done so. Will saw only two possible types of response during these episodes: to remain silent or to respond in kind, although he knew from experience that both modes of responding merely exacerbated the situation. He expressed bafflement as to the reasons for Janet's reactions to his typical response behaviours, but nevertheless chose silence as the lesser of two evils.

> I don't say nothing otherwise it gets out of control .... If I get upset, that makes her upset ... But if I keep quiet, that bugs her more. So human behaviour is very strange.

Will became most aroused when he considered that Janet had become angry with him without good cause. On those occasions, his response was to leave the scene by, for instance, going for a drive. He had also come to realize, however, that he and Janet needed to talk more to each other about matters each considered to be important.

During the second and third interviews, Janet and Will had several sharp exchanges. In the second interview, two exchanges indicated Will's exasperation with Janet for continuing to ruminate on the events surrounding Denise's birth and subsequent to it. One interaction concerned Janet's wish for more printed information about premature babies.

> Janet: Over Christmas, Will said that he bought me a book for Christmas ... I was sure you'd (to Will) bought me a book on premature babies.
>
> Will: Gee, I was just saying try to get your mind off it.
>
> Janet: No.

In the third interview, Janet reacted in anger when Will stated that she had not wanted to pay off the mortgage as quickly as he had.

> Janet: That's not true.
>
> Will: It's true, Janet.
>
> Janet: It's not true. You tell people that and it's not true.

Despite their disagreements, Will expressed the belief that Janet had become less volatile, more confident in expressing her opinions, and more willing to hear his side of an argument.

Will and Janet shared several areas of agreement. They both believed that couples needed to participate in leisure activities together but that each should also have a circle of friends with whom they could socialize separately. They also agreed on the importance of raising Denise to have a set of religious beliefs to guide her through life. For this reason, Will, originally a member of the United Church, had not only married Janet in the church to which she belonged, the Roman Catholic church, but had agreed to Denise being baptized a Catholic. He also willingly attended Mass each Sunday with Janet and Denise.

Pam and Kevin Both Kevin and Pam viewed their marriage as a good one but their different modes of dealing with stress and their lack of communication concerning this matter strained their relationship for a number of months after Corey's birth. The development of this problem and its gradual resolution evolved through two separate phases. During the first phase, Pam, in her emotional distress over Corey's recurring relapses, interpreted Kevin's minimal display of emotion as betraying a lack of fatherly love.

> I had the attitude that he really didn't care because he really didn't show his feelings ... he was calm, cool and collected. I was just shocked by the way he acted.

Another aspect of Kevin's behaviour added to Pam's unhappiness. His seeming reluctance to discuss the feelings Corey's illness was arousing in them both, left her feeling lonely and ignored.

> It seemed like every weekend I was left here alone with another kid and I needed him and - he was there, I can't say

> he wasn't there - but he just wasn't expressing his feelings and I was expressing mine and I'd get nothing back like "I understand."

Part of the reason for Kevin's seeming lack of empathy, lay in the approach, similar to that of Will, which he had adopted to deal with the occasions when Pam spoke to him in a hostile manner. He had decided that the most sensible strategy to avoid aggravating Pam's emotional state, would be to say as little as possible.

> She was always snapping at me but I knew she was under a lot of pressure. So I just put it down to that and didn't say very much ... [She] was always so upset I figured if I got upset she'd get much worse.

The particular dynamic between Kevin and Pam and between Will and Janet has been noted by other researchers. Shosenberg and Lennox (1985) provide an account by a mother.

> My stress ... was very high. I really didn't feel my husband understood. We tried to talk things out but his inability to be there became interpreted by me as an unwillingness to be there. My husband retained a good deal of his stress for fear he would upset me more.

The second and more positive phase in the development of the relationship between Pam and Kevin, had commenced during the later months after Corey's homecoming. As a result of their own reading about prematurity and of their dialogue with the researcher, they had begun to discuss and understand their individual experiencing of the events leading up to and following Corey's birth.

> Pam: We've got a lot of understanding from each other now in these months reading and hearing things about those other premature babies. Now we're

> expressing our feelings, what we went through: "Remember this, remember that?" So now I'm getting his point of view, but not then .... Now I know he's holding everything inside and when he's ready, he'll talk about it. And he knows how I am, I'm sure.

Kevin: (Nods).

Based on this statement by Pam and Kevin's concurrence, it would appear that the experiencing of having Corey had resulted in a deepening of their relationship.

Beth and Philip Philip and Beth had known each other since they were students in the same high school. They had been drawn to each other in part because they had both come to believe that it was important to question generally accepted societal values and practices and when necessary, to seek out or develop their own alternatives.

They attempted to practise their ideals in working on their relationship. This was not easy during the many months of continuing worry about Martin's precarious health. The impact of this stress, as well as the demands of their many other responsibilities, at times led them to withdraw from each other or to communicate inadequately with each other. However, they were also able to be aware of each other's needs.

Like other mothers who delivered premature infants (Evans, 1985), Beth realized her husband's need for support, particularly during the period when she was hospitalized. She was concerned about his exhausted appearance when he visited her because she was aware of the double workload he was carrying as a fulltime employee and as a temporary homemaker with the responsibility for the care of their two young sons.

Beth was unable to maintain awareness of Philip's needs during a period of intense strain she experienced in the weeks after Martin's birth. She was preoccupied with her anguish about the many physical problems he had developed, and with her feelings of guilt concerning her inability to breastfeed him. She felt estranged from Philip and was able to discuss her feelings only with a primary nurse whom she had come to know and trust.

Beth's withdrawal from Philip, although temporary, was nevertheless a sign of unusual strain she was living under, because for most of the years they had known each other, she and Philip had depended mainly on each other for companionship. They had moderated their mutual over-reliance after a caution by a counsellor early in their marriage, to spend more time with other people. One of the ways they had chosen to implement this advice, was to visit Martin separately, enabling their relationship to shed some of its intense quality.

> Philip: I remember talking to a counsellor when we were first married ... and being told we should not spend so much time with each other ... and that sort of always stayed with me ... Over the course of the year [of Martin's hospitalization] we spent more time apart than we ever had before. There was never an evening where one of us wasn't out at the hospital ... I can't really say that that was bad for our relationship. It did give us a bit of space.

During an interview, an interaction raised the question whether the results of their separate visits had proved completely palatable to Philip. Beth had stated that during her visits to Martin in the NICU, she had formed close relationships with a number of people. Looking at Philip, she had then added, "But I don't know how you viewed that." Philip chose to reply by addressing his comments to the researcher.

> Well ... since Beth had not been in the career world - she used to be a teacher - she hasn't had a lot of interaction with adults so that gave her a new lease on what life was really about, talking to other men and women.

The fact that Philip did not directly respond to Beth's question and avoided mention of his feelings regarding her relinquishing her reliance on him as her main source of emotional support, can be interpreted in various ways. He may not have been as comfortable with this new development as he wished to believe, but did not yet feel prepared to discuss his feelings with Beth. Alternatively, he may not have wished to hold such a discussion in the presence of a third party. A third possibility is that he may have interpreted Beth's question as being intellectual in nature and therefore supplied an intellectual answer which he directed out of courtesy to the interviewer.

A more clearcut example of inadequate communication between Philip and Beth concerned Beth's expression of fatigue. Her excessively busy days after Martin's arrival home, often left her feeling very tired and she would inform Philip of this on occasion. He would perceive her statement as proof that she was casting herself in a martyr role. Sometimes Beth agreed that this might be so. At other times she resented Philip's interpretation because she felt justified in expressing the weariness she was experiencing. She and Philip did not explore the possibility that her assumption of the martyr role may have been a disguised plea for nurturing.

Beth's need for nurturing was only being partly met by members of her various support networks, consequently she looked to Philip as an important provider of emotional support. For this reason, among others, she felt the need to spend more time alone with him. This was not always possible and even when they had the opportunity to spend time together, their needs sometimes conflicted. There were evenings when she was eager to go out after being confined within the home all day, whereas Philip wished to stay home after spending a tiring day at work. They had begun to accept the fact that their needs would differ at times and that they would have to accommodate each other.

Philip and Beth had also come to accept that their opinions differed on a number of subjects. Rather than viewing these differences as a negative attribute of their relationship, Beth considered them proof of the strength of that relationship, and as a sign that each of them was remaining true to beliefs developed and held to be important. Yet she also realized their continuing development as separate persons would be a continuing test of their relationship.

> We disagreed before Martin came. We argue a great deal, it's a great part of our relating (laughs) and I think we'll

> continue ... As we grow older our differences are greater as we're coming more into our own rights as human beings, rather than being "the couple" ... And I view that as a positive thing. I like it (laughs). It's nice to have the companionship. I hope it can endure the individual growings.

Instrumental support. The socialization of parents into the belief that housework and child care are mainly the province of women, caused conflict between several couples because of fathers' willingness to perform only some of these services and only at certain times. Some mothers found it difficult to relinquish specific traditional duties even when their husbands were prepared to discharge them. Parents appeared to be at different levels of awareness and possibly of preparedness, to question the prescribed gender roles which were causing disharmony between them.

Sharon and Jim Throughout the course of interviews with Jim and Sharon, there was only one occasion on which open conflict between them surfaced. It related to their recollections of the extent to which Jim had assisted in the physical caretaking of their children. Jim's minimal efforts seem to have been mainly due to his assumption that once mothers had recovered from childbirth, child care became their total responsibility.

> Jim: By the time Melissa came home, Sharon had recuperated from her stay in hospital so I just says, "You can handle that."
>
> Sharon: You never helped me with Seth either though.
>
> Jim: I got up with you a few times with Seth. I didn't actually do it myself but I got up with you.

Sharon: Ya, because you woke up so you just sat up. But it never worked out the time you did try. You usually ended up waking me 'cause you couldn't find the diaper or he couldn't find this or something.

Sharon's resentment arose at least partly from the fact that she intensely disliked having to break her night sleep in order to meet Melissa's needs when she woke and cried, and that Jim had remained firm in his refusal to relieve her from time to time.

Res: Did you ever coax Jim into getting up and giving a feed?

Jim: No way (laughs).

Sharon: Nope.

Res: Not even the 6 a.m. one?

Sharon: Nope.

Sharon attempted to be fair in her assessment of Jim's fathering since the birth of Seth.

> With Seth he was a lot more nervous, he was scared to do anything with him ... Melissa was so many months old and he had done a lot more with her than he ever did with Seth in his lifetime.

At another point, however, Sharon stated that although Jim had helped a little more with Melissa's care than he had with Seth's care, his help had been limited to occasionally giving her her bottle during the day.

Barb and Noel. Because Noel had given no indication prior to Annette's birth that he would be disposed to take his responsibilities as a father seriously, the extent of his involvement in Annette's care had been both unexpected and a source of relief to Barb.

> I've been very surprised that he's shared as much as he has. Some of them won't have anything to do with kids ... I kept hoping that Noel would. A lot of people can't believe he's so involved with her.

Noel had sole care of Annette on the nights that Barb worked outside the home. He fed her, played with her and put her to bed. He refused to bathe her and would change her wet diapers but not her soiled ones, an exclusion which annoyed Barb.

Noel had also restricted his participation in Annette's care in another way which caused hardship to Barb. He did not offer to share in attending to Annette's needs when she awoke during the night. Barb therefore took the step of stipulating that she could only cope with six nights of broken sleep each week, and that he would have to be responsible for Annette's care during the seventh night.

It is doubtful whether Noel would have participated as much as he did in Annette's physical caretaking, if Barb had not had to work outside the home. Although realizing that spending time alone with Annette enabled him to learn caretaking skills, Noel believed that it was preordained that fathers did not perform these tasks if mothers were available to do so.

> I think it was a good experience for the husband anyway, to be home with the child without the mother being there all the time, because you can deal with certain situations, like I feed her and change her ... I probably wouldn't have done it if she [Barb] were there, well naturally I wouldn't.

Noel also appeared to view housework as the main responsibility of mothers, agreeing with Barb that their division of labour had not changed since Annette's birth. Although unhappy with this state of affairs, Barb had allowed it to continue.

> He always did most of the yard work and I'd do the housework ... I do the laundry. He doesn't cook supper, doesn't do dishes, he's never touched a vacuum cleaner.

Pam and Kevin The relationship between Kevin and Pam had been enhanced by Kevin's involvement in child care which extended beyond that practised by most fathers. After arriving home from work at 2 a.m., he gave Corey his 4.30 a.m. feed and diaper change. He also helped care for Corey during the day and was not embarrassed about discussing his parenting limitations, acknowledging he sometimes found Corey's cues more difficult to read than Pam did.

Kevin shared as well in providing Jill's physical and nurturing needs. During one interview, he left the room to bathe her and put her to bed. On another occasion, he held her in his arms after she had woken from a nap, while he continued to contribute to the interview.

Home maintenance appeared to be organized along conventional lines, with Pam responsible for housework and Kevin mainly responsible for outdoor work.

Beth and Philip Philip and Beth had both read widely about parenthood and discussed topics relating to it. In addition, Beth was a trained facilitator of parent education groups. Although their self-education had made them observant of their own and others' marital and parenting practices, they still adhered to a great extent to traditional gender roles, particularly with regard to housework.

Philip justifiably saw himself as a father committed to, and enjoying his children more than many other fathers.

> It seems as though the men that I talk to in the working world don't have the same type of relationship with their child as I have with mine. I enjoy being with them and I like doing all the things that I can with them.

His involvement with the children's physical care had commenced with the birth of John, the eldest child.

> Res: So when they [the two older boys] were little, you'd be doing all the things like diapering, giving them their bottle ...
>
> Philip: Oh sure. With John, every time he made a little squeak ... one of us would be up jumping, particularly Beth ... When Stephen came along, Beth had quite a bit of burnout because of constant getting up in the night with John requiring [breast] feeding ... so more times than not I'd end up by taking Stephen in the night. That was my role. But diapering, gosh yes, lots of that. I just can't breastfeed (laughs).

With regard to Martin, Philip was particularly active in monitoring his tracheostomy and the equipment needed to humidify the air he breathed and to suction secretions from his lungs. Philip was as concerned as Beth about Martin's feeding problems, as well as with developing closer emotional ties with him than had been possible during his long stay in the NICU.

Philip also displayed sensitivity with regard to the older two boys' emotional needs, especially their wish to be considered as important to their parents as Martin was. Before the commencement of one interview session, Beth and Philip invited the researcher to observe the bedtime ritual Philip had developed as a form of nurturing for John and Stephen. They shared a bedroom with Martin and while Beth attended to his needs, Philip swiftly helped the other two boys to undress and slip into the bed they shared. He then administered several moderately firm strokes on each boy's back as he lay relaxed on his side. Both boys were asleep within a few minutes. Philip later explained that the manual contact he had applied to the boys' bodies was very similar to that used when performing percussion several times daily on Martin to loosen mucous in his lungs, a procedure Stephen and John had often observed. To enable them to feel they were receiving the same special treatment as Martin, Philip had decided to perform a type of percussion on them and had found that this practice not only served his original purpose but had resulted in their falling asleep sooner than they previously had. It had therefore become a nightly ceremony that both father and sons found rewarding.

There were times, however, when Beth felt Philip was not as deeply involved with the children as he should be. Differences of opinion as to how much time they should each spend with the children had caused friction between them. Beth acknowledged, however, that when Philip spent more time with the boys, she often found herself interfering with his interaction with them, as if she was finding it difficult to relinquish even temporarily, her role as primary caretaker and nurturer.

With regard to housework, there was less sharing of tasks between Beth and Philip. During Beth's six-week stay in hospital, Philip had been required to do the housework. After Beth had returned home, the conventional division of labour was reestablished with Beth responsible for housework and Philip for home repairs and outdoor maintenance.

Despite the tendency of Philip and herself to question socially imposed practices, Beth saw them both still adhering to stereotypical female/male roles in their marriage.

> The only difference I can see off of the roles that I saw in my parents versus the roles that I see for Philip and I now, is that perhaps we're slightly more aware, only slightly. I don't see any great reams of progress.

Janet and Will The most profound change in gender roles was experienced by Will and Janet. When Janet was recalled to work approximately 5 months after Denise's arrival home, Will was unemployed and he accepted as a matter of course that he would become the fulltime homemaker. The succeeding weeks initiated a change in his previously held views about the life of a housewife. Janet recalled that earlier in their marriage, when Will was employed outside the home, he was not aware of the amount of work she performed each day as a fulltime homemaker.

> Will always used to say to me, "Well, you talked to your mother and sister. What did you do all day?" I mean, that was while I was doing dishes, while I was folding diapers. I had the phone on my shoulder. I was doing something.

By the final interview, Will had spent approximately 6 weeks in his new role and had found it to be a demanding but enlightening experience. He believed couples' relationships would be enhanced if more fathers could have the same experience because they would learn, as he had, about the number and diversity of tasks fulltime homemakers were required to perform.

> I think it would be a good experience for most fathers ... because you've really got a chance to see what a housewife's role is. It's not to be taken for granted, that's for sure .... It's more than changing diapers, it's being in the home doing the things you've got to do ... not talking on the phone all day because when you're home you can see that you don't have that much time to talk on the phone. I think it would be a benefit to a lot of relationships to see, you know.

Will not only performed the many physical caretaking and nurturing acts Denise needed each day, but he also took her to the public health clinic for routine examinations and to be immunized against various diseases. As well, he accompanied her to appointments with the paediatrician.

Janet's initial uncertainty about Will's propensity for fatherhood, was replaced by delight as she observed his interest and adeptness in caring for Denise.

> When I was pregnant, I would think, "I wonder what Will's going to be like as a father?" I didn't know what he was going to be like. And he's just remarkable.

Although Janet stated that Will did everything, she willingly undertook household and child care tasks each evening. Furthermore, she appeared to find it difficult to divest herself of her homemaker role, still feeling obliged to do heavy cleaning even when fatigued from a day in her workplace.

> Will makes supper every night .... I come home ... and right away I start getting ready to feed Denise ... then I usually do the dishes ... I play with her ... then I have to give her her bath and give her her feed and put her to bed ... And it's almost 10 o'clock. And then ... I may want to sit and watch TV ... I have to start getting organized and maybe wash the floors ... or do something like that ... And yet I'm tired too.

A number of researchers in England and the United States have found that fathers of premature infants feed, diaper and change their infants' clothing more often than do fathers of fullterm infants, both in hospital and at home (Parke, 1981). The Australian study by Lissenden (1984) and the Canadian study by Minde et al. (1980) provide further confirmation. On the other hand, two Canadian studies show that fathers of premature infants do not perform significantly more physical caretaking tasks for their babies than do fathers of fullterm infants (Evans, 1985; Marton, Minde & Perrotta, 1981). In the study by Marton et al., mothers expressed the wish for more assistance from fathers in all areas of work in the home but especially with the physical care of their babies.

There is very little information on fathers' attitudes to and involvement in the nurturing of their VLBW premature infants.

Jeffcoate et al. (1979) report that of the 14 fathers of premature infants in their study, only 35% of them perceived nurturing to be part of their fathering role.

It is possible that on average, fathers of VLBW premature infants may be more involved in child care and housework than fathers of fullterm infants, but the latter group of fathers generally have such minimal participation in those tasks, that the extra effort by fathers of VLBW premature infants may still not be adequate to relieve mothers sufficiently of their heavy workloads.

Summary

Both formal and informal sources of support were inadequate to meet the needs of most couples. Because of this, most mothers at times felt deprived of all forms of support. Fathers appeared to be less affected, with the father of the most seriously ill infant suffering the most.

There were two sources of formally organized support for parents, one of which was to be found within hospitals. The two NICU's had recognized parents' need for emotional support and informational support by establishing parent support groups. However, the timing of meetings and fathers' wariness of personal disclosure were two factors that contributed to the groups achieving only limited effectiveness with mothers and almost none with fathers. After infants' discharge, home visits from public health nurses were the only form of organized assistance for parents. A few parents obtained support from community-based professionals.

Assistance from family members varied. There were few grandparents available, willing or able to offer parents either emotional or practical support. In some cases, geographical distance was an impediment but even grandparents living close to parents were not always helpful to them. The reasons for grandparents' limited supportiveness included their own emotional reactions to their unusual newborn grandchildren, preexisting problems in grandparent/parent relationships, preoccupation with their own personal concerns, and in some cases, a lack of interest in their new grandchildren.

Parents received mixed support from other relatives. Some siblings lived too far away to be physically present very often, or at all. Mothers had more support from siblings than did fathers, with mothers' sisters usually proving helpful, possibly because they were mothers themselves. Of the four fathers with siblings, only one felt fully supported by them, while another received qualified support from his only brother who was also his only sibling. Only two relatives by marriage were reported to have caused pain by making insensitive remarks.

With regard to social networks, fathers appeared on the whole to have fewer friends than did mothers but some of them obtained emotional and practical support from co-workers. Fewer than half the mothers seemed to have more than one friend whom they saw regularly and from whom they obtained emotional and/or concrete forms of assistance. A number of parents had, or were building, social networks among their neighbours. These parents not only sought increases in their social circles, but like many North American parents (Powell, 1979), they had found their neighbourhoods to be ideal milieux for reciprocal informal child care.

The reactions of various support network members to the newborn VLBW premature infants and to later events concerning them, appeared to have multiple origins. Many members were taken aback at finding themselves confronted by a childbirth situation foreign to them and did not know how to respond appropriately. Most of them lacked knowledge about prematurity and its sequelae and some feared the infants would not survive. Some were affronted by, or uncomprehending of parental decisions due to communication problems between the two parties. Most parents did not exhibit awareness of the reasons underlying network members' offending behaviours and members seemed oblivious of the impact of their comments and actions on parents.

Having a VLBW premature infant appears to have strained the relationships of four of the five couples, the extent varying from one marriage to another. The peak in marital harmony appeared to have occurred while mothers were hospitalized and they were impressed and touched by their husbands' loving attention and by their competent management of domestic matters. At the time of the final interview with each couple, most spousal relationships were still being affected by the emotional turmoil parents were experiencing as a result of the many problems they continually had to cope with. This distress was not the only cause of conflict between couples. Preexisting unresolved communication problems, individuals' personality characteristics, and mothers' feelings of resentment at the imbalance in gender-based divisions of labour, were contributing to the development of marital friction. In only one case was there unanimous agreement between spouses regarding the total effect on their relationship of their experiences as parents of a VLBW premature infant.

Socialization into gender roles seemed to be a prime factor in depriving spouses of mutual support. Mothers did not seem to feel free to assert their right to relief from carrying the main burden of responsibility for housework and child care. In most cases, feelings of anger toward their spouses appeared to be simmering just below the surface. The societal proscription on males admitting to painful feelings and seeking help to deal with them, denied fathers relief. It also bedeviled their marital relationships in two ways. It prevented fathers from feeling comfortable with their wives' expressions of emotion. As well, fathers' efforts to hide their feelings conveyed distorted information to their wives about their authentic feelings, and wives' resulting negative reactions led to further marital disharmony.

The uneven amount and quality of support most parents received from both formal and informal sources, appeared to emphasize for them their atypicality as parents of VLBW premature infants, with an accompanying sense of separateness from the mainstream of parents and therefore a sense of social isolation. There was also in some parents a sense of disillusionment occasioned by the lack of understanding from those they had most counted on for support.

CHAPTER V

Discussion

Introduction

In the previous chapter, the accounts by ten parents of their subjective experiences revealed individual parents' unique perceptions and the meanings of their experiences held for each of them. From the totality of parents' narratives there emerged common experiences sufficient in number to be grouped into five main themes. These themes together comprise a patterned structure that enables a deeper understanding of the experiences of parents having a VLBW premature infant.

In this chapter, aspects of parents' experience contained in the five themes will be discussed with reference to the purposes outlined and the questions posed earlier in the study. The practical implications of the study's findings and their implications for future research will be presented, as well as recommendations from the parents themselves.

The Birth of a VLBW Premature Infant as a Crisis for Parents

Unlike other studies, the present study explored in depth with parents their experiences from the conception of their infants until several months after their babies had joined their families at home. This comprehensive exploration enabled the researcher to obtain sufficient information to examine, among other questions, whether having a VLBW premature infant constituted a crisis for parents, as generally claimed by other researchers (Bidder et al., 1974; Minde et al., 1980; Silcock, 1984).

Parents experienced the gestation, birth and early parenting of their infants as a series of critical events, each of which profoundly affected their day-to-day feelings, thoughts and activities, although the severity and duration of emotional and behavioural manifestations varied from one parent to another. These departures from parents' usual way of being is in accord with the definition of crisis as a state of being triggered by a precipitating event and manifested in cognitive and affective disruption unusual for the individual in question (Bloom, 1963).

A sense of helplessness has come to be considered a hallmark of the crisis state (Caplan, 1966; Fleischman, 1986) and it pervaded parents' lives as they were plunged into environments that were alien and intimidating. Parents often felt they were no longer acting upon their worlds. Instead, they saw themselves as objects in their worlds, acted upon by people and external events over which they could exert little or no control. Lack of knowledge concerning the nature and causes of crucial events led parents to experience themselves as powerless, lacking the resources to understand and influence the people and forces affecting their lives.

Mothers generally appeared to experience more painful emotions and more prolonged crisis behaviour than did fathers, a finding in accord with those of several empiricist studies (Jeffcoate et al., 1979; Yu et al., 1981). Mothers' more intense crisis states may have been due to their more intimate involvement with their infants from the moment of conception. Jeffcoate et al. suggest that mothers' more extreme distress may also arise from the fact that their weeks of separation from the hospitalized infants prevented them from adequately performing their personally and socially valued maternal roles. It is important to point out that the researcher found it difficult to draw fathers into talking about their feelings, therefore the depth and length of their crisis states may have been greater than they reported.

Parents' crisis behaviour ranged from moderate and relatively short-lived to intense and prolonged. Empiricist studies have also reported differences in type, duration and depth of crisis states among mothers (Shosenberg, 1980; Silcock, 1984) and among fathers of VLBW premature infants (Newman, 1980). Crisis theorists like Auerbach (1983), Caplan et al. (1965) and Taplin (1971) are in agreement that the interplay of many factors will determine the type, intensity and duration of crisis states. With very few exceptions (Minde et al., 1975), empiricist studies have fallen short in exploring the interlocking factors which led individual parents to experience crisis states varying in nature and severity.

A number of these factors emerged during the present study because of its concentration on relatively free-flowing but intensive dialogue with parents. During the course of interviews, parents presented information about their belief systems, their self-concepts, accounts of their own nurturing as children and their relationships with their parents and siblings, their life experiences and the quality of their current personal and family relationships.

On occasion, parents themselves described what factors had played a part in guiding their responses to events. More often, the researcher was obliged to achieve a comparable though more tentative result through reflecting on parents' accounts and her own perceptions, culminating in that "precarious leap" (Colaizzi, 1978, p. 59) from the verbal to the meanings behind the verbal.

The Four Psychological Tasks of Parents of Premature Infants

The concept of the necessity for parents to complete four psychological tasks in order to work through the crisis-inducing situations relating to the births of their infants, was originally designed to detect warning signals with regard to mothers' difficulties in accepting their premature infants (Kaplan & Mason, 1960). It is this researcher's belief that the maternal bias of the concept reflects the values of the academic community in the 1960's and that the concept applies to fathers as well.

The relationship of the 10 parents' experiences to the four tasks will be briefly summarized.

Anticipatory Grief - Temporary Withdrawal from Infants for Fear of their Impending Deaths

Both fathers and mothers found it difficult to answer questions relating to this task. One father refused to visit his infant daughter for two weeks after his first visit but his reluctance may have been due to reasons other than anticipatory grief, such as the shock at his first experience of the NICU.

One mother appears to have experienced strong enough grief to have refused to prepare a room for her baby at home until she was sure she would live. Another mother held to a similar decision for the first few postpartal weeks. A third mother's prayer on first seeing her infant in the NICU that the baby not be hers, may indicate her wish at the time to avoid becoming attached to such a frail infant.

Feelings of Failure

Parents almost unanimously denied having experienced self-recrimination for failing to produce a healthy fullterm infant. Instead, fathers described feeling disbelief that such an event could have happened to them and most mothers wondered guiltily if they had in some way caused the untimely births, a common phenomenon among mothers of premature infants (Klaus & Kennell, 1982; Shosenberg, 1980a).

It is possible that parents' responses may have in some cases constituted a form of denial. It is also possible that like other parents in similar situations (Kaplan & Mason, 1960; Silcock, 1984), those couples who had struggled through troubled pregnancies or had had infertility problems, may have felt triumphant at having delivered a living infant at all. As well, media coverage of advances in the technology for saving the lives of VLBW newborns may have helped parents feel less isolated from mainstream parenthood.

Resuming Relating to Infants When They Have Begun to Improve

Parents' frequent visits to their infants and their participation in their care in the NICU would seem to indicate that the process of becoming attached to their babies was never seriously interrupted.

Understanding the Needs of Premature Infants

Three couples expressed a wish for more information about the special needs, possible problems and normal development of premature infants, and read whatever material they could find. A mother who had not evinced interest in improving her knowledge of premature infants, displayed continuing apprehension about the possibility of her infant daughter showing signs of abnormal development in the future. Her fears had commenced during pregnancy, after her sister's troubled pregnancy had culminated in the delivery of a Down's syndrome child, and she may have feared receiving confirmation of her worst expectations in the printed word.

This mother had the least satisfying relationship with her VLBW premature infant of all the parents, according to her own reports and the observations of her researcher, although she had visited and cared for her faithfully in the NICU, and on one occasion described her as "a joy". She was the least knowledgeable concerning parenting of all the mothers. In addition, she had described a childhood lacking in parental love, and a marriage offering her sparse support of any kind. It may be, as Herzog (1979) proposes, that mothers need to have received and to be receiving nurturing themselves in order to be able to nurture their children.

The concept of the four psychological tasks appears useful as a broad framework from which to assess parents' progress through their crisis states. However, this researcher agrees with Silcock (1984), the only empiricist to study the concept in depth, that the problems parents face are far more complex than indicated by the four tasks.

Fathers

A number of factor influenced fathers' decisions and activities.

Fathers' Special Roles

Confirming previous research (Benfield et al., 1976; Kennell & Klaus, 1982), paternal accounts painted a picture of roles unique to fathers of VLBW premature infants. It was to most of the fathers that obstetricians and neonatologists provided the first information about the newborn status of their infants, and fathers were the first parents from whom most newborns received a visit, usually within the first hours after their transfers to the facility. Fathers then reported on these visits during their first postpartal visits to their wives and accompanied them in most cases on their first visits to the NICU. Working fathers also were obliged to maintain the home and organize care for other children while still working in their fulltime occupations and visiting their wives and babies nightly. Fathers thus played a far stronger supportive role for their hospitalized wives than is usually the case after the birth of fullterm infants.

Confirming other findings (Kennell & Klaus, 1982; Wright & Zucker, 1980), this study revealed a further difference between the fathers in this study and the fathers of fullterm infants. This relates to the early involvement of fathers, although in varying degree, in the caretaking and nurturing of their VLBW premature infants in the NICU. Their participation extended over many weeks and in the case of one father, over one year. Such intense parenting activity by fathers has been attributed by some researchers (Marton, Minde & Perrotta, 1981; Newman, 1980) to the fact that parents are equals in their capacities as visitors in the NICU, with both of them receiving encouragement from staff to interact with and care for their babies. Marton et al. comment that in the singular environment of the NICU, gender role stereotypes do not apply as they do elsewhere, and they themselves found spouses performing very similar tasks and nurturing activities with their infants. However, like many other fathers of premature infants (Evans, 1985; Jeffcoate et al., 1979; Marton et al., 1981), the involvement with their infants displayed by the five fathers in the present study, diminished once their babies had come home except in the case of one father who became a fulltime homemaker out of necessity.

Gender Role Expression

In addition to their decreased involvement with their infants at home, fathers indicated their adherence to their socialized gender roles during the interview process. Like many other fathers of premature infants (Benfield et al., 1976; Trause & Kramer, 1983), all five fathers seemed reluctant to discuss in any depth their emotional responses to the stressful events they had, and were experiencing. Their avoidance appeared to take two forms. Firstly, they confined themselves to brief statements containing low-affect adjectives such as "upset", "worried" and "shocked" when describing their emotional reactions to specific events.

A second phenomenon soon emerged during interviews. Most fathers assumed the roles of family historian and technical expert. These roles appeared important enough to two fathers to lead them to interrupt their wives and even usurp the role of narrator in order to be the one to recount events and provide medical detail about their wives' and babies' health problems. One father had kept a diary from the day of his daughter's birth and at one point read extracts from it aloud. According to David and Brannon (1976), these fathers' behaviours may derive from a dimension of the male gender role which requires men to appear knowledgeable as a means of appearing in command of a situation. This reason may well have special application to the fathers in this study, given the number of situations which arose and over which they had no control. Whatever the reasons, fathers succeeded in providing minimal information concerning their emotional responses to people and events.

Because four of the fathers possessed only limited family and social support networks, it seems puzzling at first glance that they would not have welcomed the opportunity attend parent support group meetings. Their socialization, instilling the view that men should be able to deal with painful affective matters without assistance (Goldberg, 1980), may well have played a role in their abstention.

Fathers' past experiences and current self-concepts may also have prompted fathers to avoid joining groups. One father described himself as coming from a home where feelings were not discussed openly and acknowledged that he still did not find it easy to do so. A second father saw himself as a "loner" while another father described himself as someone who usually "keeps himself to himself." As the youngest child in a large family, a fourth father grew up feeling isolated from his siblings and this feeling of separateness from others may have persisted into adulthood. Similarly, the fifth father recalled that as an only child, he had grown up feeling different and therefore apart from other children, and that this feeling had stayed with him over the years. The research literature contains no discussion of the individual differences of fathers who participate in parent support groups as opposed to those who do not.

Grandparents

This study highlights the potential of grandparents to be either valuable sources of support to parents or conversely, to add to their burden of stress.

Some grandparents looked to parents for understanding and comfort while they grieved over the birth of a VLBW premature grandchild. This was especially true in the case of three parents whose mothers required emotional support for months while they came to terms with their feelings about their tiny, ill new grandchildren. A grieving process has been found to commonly occur in grandparents of infants with various types of aberrant characteristics (Luterman, 1979). Having to offer their parents support at a time when they themselves felt most in need of such support, involved an unwelcome role reversal for parents similar to that experienced by other parents of atypical infants (Luterman, 1979).

In perhaps the only instance to date when a grandmother's views were elicited by researchers (Shosenberg & Lennox, 1985), she provides insights into the problems of grandparents following the births of their VLBW premature grandchildren. This grandmother states that, like many parents, most grandparents lack accurate information about prematurity's etiologies or the problems and typical development of VLBW premature infants, yet without this knowledge they can be of only limited help to parents. Lack of such information also hinders grandparents' efforts to supply general information about premature infants and current information on their new grandchild's medical problems and present condition, to relatives and friends who often look to grandparents to fulfil this role. The grandmother ends her contribution by expressing the wish that grandparents be included in organized efforts to provide parents with informational and emotional support.

Siblings

The accounts of the three multiparous couples revealed varying degrees of insight into the problems occasioned for siblings by the premature birth of a very sick baby. The parents with the older infants reported experiencing more prolonged troubled behaviours from siblings than did the couple with the youngest infant, and the two couples therefore experienced more stress arising from the older children's actions and attitudes.

According to parents, the reactions displayed by siblings to the arrival of a VLBW premature infant in the family, operated in circular fashion on family relationships. The older children appeared to experience mixed emotions about a new child's arrival and subsequent presence in the home. They expressed their feelings in various ways, impacting on parents who then responded in turn and their responses evoked answering behaviours from the children.

Parents generally appeared unaware of the fact that siblings would have been affected by events leading up to the births of the VLBW premature babies. The older children would have been upset by the general atmosphere of tension at home while their mothers were hemorrhaging. Like other siblings of premature infants (Trause & Kramer, 1982), they would have been frightened by the emergency situations necessitating their mothers' sudden departures for the hospital. They would have been distressed by their mothers' absence from the home and would have had to tolerate unsettling deviations from familiar family routines while their fathers struggled to cope with multiple responsibilities. Siblings may have experienced shock and fear at their first sight of the tiny, ill new babies. Like other siblings of atypical infants, they may have indulged in magical thinking, believing they were responsible for the new baby's abnormalities, and in the course of babies' subsequent illness, they may have feared they would acquire the same problems or even that they would die (Bocian & Kaback, 1978). They would have witnessed the continuous emotional distress of their parents during the weeks of the new babies' postnatal illness, and possibly felt deprived during the long hours their parents spent in the NICU with the new babies.

Once the infants had arrived home, siblings would have had to adjust to new family routines to accommodate the needs of the newest family member. They would have become aware of the fatigue that prevented their parents from spending as much time with them as before. They would also have to live at times in an atmosphere strained by communication problems between their parents.

Parents reported caring behaviours by siblings in the first months after the infants' homecomings signalled the arrival of potential new playmates. However, parents reported subsequent displays of predominantly negative behaviours by siblings, accelerating in one case when the infant began to walk. Some of the behaviours may have arisen in response to parents' lack of awareness, reflected in their words and actions, of the psychological impact on older children of the change in their relationships with their parents as a result of the demands on parents of the new baby. Like other parents of premature infants (Owens, 1960), parents differed in their awareness of, and sensitivity to their older children's problems. One of these problems involved the necessity for the children to forego their positions as the major foci of love and attention from parents and others, and share or even forfeit the limelight to the new babies. This situation, as well as the babies' absorption of so much of parents' time and energy, seem to have aroused resentment in the siblings toward their mothers and the babies. They expressed this in numerous ways but also adopted various infant caretaking practices perhaps to win the attention and approval of their parents and particularly of their mothers. Two of the three fathers attempted to spend as much time as possible with the older children, aware to some extent of their emotional needs.

The cumulative effect on parents of the intermittent negative behaviours of siblings, coupled with parents' growing realization of their children's unhappiness, was to add further to the burden of guilt mothers experienced and to increase the feelings of frustration and inadequacy both parents felt. They did not posses the knowledge to fully understand their older children's problems nor did they possess the time or energy to seek it out.

Professional assistance in understanding siblings' feelings, needs, worries and questions about the VLBW premature baby, has proved helpful to both parents and siblings (Aradine et al., 1980). Such aid may have prevented or at least ameliorated the situation in the homes of two of the couples in which siblings were still exhibiting behaviours signifying their unmet emotional needs 16 months after the births of the VLBW premature infants.

Although existing research on the effects on siblings of the births of infants with physical and mental handicaps shows that they share common experiences with the siblings of VLBW premature infants (Bocian & Kaback, 1978; Hymovich & Chamberlin, 1980), the latter group of children often begin to suffer before the birth of the infants.

The very limited existing research has paid scant attention to their experiences during this period of time.

Summary

The researcher is aware that the findings of this study are based mainly on the accounts of parents and that the perceptions of the same events by their co-experiencers may be different. Nevertheless, certain findings of this study confirm those of several other researchers. In addition, they highlight examples of theoretical weakness as well as areas of parental experience hitherto neglected by researchers.

The present study also reveals the value of the phenomenological approach. Findings enlarge on those of researchers employing the empiricist approach, as well as uncovering depths of human experience beyond the reach of that approach's practitioners.

Limitations of the Study

It is important at this point to restate and enlarge on the limitations of the present study. Firstly, the use of the self-report is open to the criticism that parents may have self-censored their contributions. This may have been the case in some areas of experience and may well have been reflected in fathers' unwillingness to discuss beyond a surface level, the affective aspects of their experiences. From a phenomenological perspective, however, this reluctance is theoretically valuable, since it is part of fathers' existential reality, reflecting their experiencing of themselves as uncomfortable in flouting the prohibition on males' public admission of vulnerability.

The more serious limitation of the present study relates to the fact that all the couples were white, married and working-class or middle-class couples, whereas many VLBW premature infants are born to poor parents, including single mothers. Omission of these parents' experience deprives us of knowledge about the needs of these most seriously stressed of parents.

Implications for Future Research

Several areas of research initiative are desirable to strengthen the theoretical underpinnings of research into the experience of parents of VLBW premature infants. These include further study of the factors influencing the degree of crisis behaviour evinced by parents so that more efficacious efforts can be developed to assist parents most in need of support as soon as possible. In particular, the processes involved in parents' weathering the vicissitudes of having and becoming attached to their VLBW premature infants, need to be studied in a wider framework than that of the four psychological tasks so that the myriad of personal, social and economic factors influencing parents are taken into account.

The necessity for the phenomenological study of specific groups is clear. Priority should now be given to exploring the experiences of poor and single parents of VLBW premature infants. There is also a need for similar studies focusing on the experiences of grandparents in order to throw more light on their unique situation, their special needs and their potential contributions to easing the lives of parents and siblings. Phenomenological studies with fathers alone are also desirable to ascertain whether they might feel more free to discuss experiences of an affective nature without the presence of a third person. Differences in openness with male and female researchers could be investigated and fathers' statements of their needs and the types of support they require, could be obtained.

Finally, to parallel the numerous longitudinal studies of the development of VLBW premature infants (McCarton, 1986), longitudinal phenomenological studies, in part employing the participant-observer method, are needed to explore more fully over time the experiences of the parents and siblings of these infants, commencing during the gestational period and following the families into the early school years of the VLBW premature children.

Practical Implications of the Study

General

In accordance with the researcher's assumption stated earlier that the purpose of all research is the betterment of the human condition, this study was undertaken with the intention of using its findings as the basis for suggestions for improving existing programs and for devising new programs to assist the parents of VLBW premature infants in dealing with their many difficulties, and thereby facilitate attachment between them and their special babies (Crnic, Greenberg, Ragozin, Robinson & Basham, 1983; Sameroff, 1981).

Parents' accounts confirmed those found in other studies (Bidder et al., 1974; Caplan et al., 1965; Mangurten et al., 1979; Silcock, 1984) indicating that parents were most in need of support at two specific periods: the period immediately after infants' births and secondly, during the first weeks and in some cases months after infants' discharge from hospital. However, it was also clear from parents' narratives that they required support at other times as well. Mothers experiencing pregnancy problems typically associated with delivery of VLBW premature infants, need emotional and informational support perhaps from public health nurse visitors concerning the possible causes of their conditions and their likely outcomes. Mothers hospitalized in high risk maternity wards also need such support.

Fathers awaiting the births of their infants alone in hospital waiting rooms, can be supported during this stressful time by volunteer "veteran" fathers recruited by the NICU, that is, fathers who have themselves had VLBW premature infants and are willing and suited to meet and offer support to other such fathers. Telephone contacts could replace personal contacts if necessary.

If social workers are informed as soon as possible which new parents are first-time parents and which parents have been delivered by caesarean section, they can pay them postpartal visits to discuss their concerns and between them decide what support services, if any, these parents need. Social workers can then liaise with the public health nurse visitors, informing them of hospital efforts to assist the mothers as well as other pertinent information. The visitors can then suggest counselling to these parents if this appears necessary in later weeks, and assist them in obtaining this help. Nurse visitors can also assist these two groups of mothers by providing them with verbal and printed information and by putting them in touch with appropriate volunteer parent groups.

Similar cooperation between NICU social workers and public health home visitors is also desirable for those parents who are neither first-time nor caesarean-delivery parents, but who show signs of unusual emotional distress at the time of mothers' discharge. Nurse visitors should offer these parents the same services as have been described above for first-time and caesarean parents.

There appears to be a need for NICU staff to initiate research into the efficacy and limitations of parent support groups and ways in which they can be improved or supplemented. There also appears to be a need for group meetings to be opened to grandparents, relatives and friends as a forum for them to learn and to express their concerns. Time should be allocated for talks on the effects on siblings of the advent of a VLBW premature infant with advice for parents on effective ways of helping their older children.

A possible supplement to the services provided by parent support groups would be a telephone "hot-line" incorporated within an existing telephone information service offered by a social agency. In response to parents' calls, an audiotape would supply answers to questions most often asked by parents of VLBW premature infants concerning their post-discharge problems and their typical developmental patterns.

In-Services for Professionals

In-services for doctors and nurses on high risk maternity wards appear necessary to effect in them a better understanding of the guilt and other emotions many of the parents experience during the tense days and weeks mothers must spend on the wards, and to emphasize the importance of dealing sensitively with these parents.

There also appears a need for in-services for public health nurses, both those who staff clinics and those who make home visits, to acquaint them with the problems faced by parents of VLBW premature infants and to provide them with information about the special problems and developmental progress of these babies so that they can offer parents much needed support during the post-discharge period.

In-services for NICU staff at which parents, grandparents and siblings would at times be present to act as resource persons, would acquaint the staff members with the many stresses the births of VLBW premature infants impose on parents and their immediate and wider families. Topics needing to be addressed include the inadequate interpersonal skills of many professionals, the impact of their personal prejudices on parents, the lack of coordinated transition of care from the NICU to community professionals, and the special, long-term as well as short-term needs of the families of chronically ill infants. Dialogue between professionals and family members at in-services would enable professionals to provide parents with insights into the limitations under which they themselves must work.

An overall coordinated, interdisciplinary approach to helping the families of VLBW premature infants, could be the focus of selected in-services for NICU staff. Two possible alternative models that might foster discussion, are the Child Development Project pioneered at the University of Michigan (Aradine et al., 1980), and the programme of multiple services for parents at the Indiana University Medical Centre in Indianapolis (Whaley, Gosling & Schreiner, 1979)

Parents' Recommendations

General

As co-researchers, parents were invited to make recommendations for ways in which health professionals could improve existing support efforts and for new projects to assist future parents of VLBW premature infants. Parents suggested the following:

1) Prenatal classes should include sessions early in the series about

pregnancy problems and about prematurity so that parents who begin to experience these situations do not feel so afraid and ignorant.

2) Each couple should have a nurse on day shift and a nurse on night shift who will specialize in caring for their baby in the NICU and be mainly responsible for providing ongoing information and support to parents.

3) While infants are in the NICU, neonatologists should schedule regular weekly meetings with parents in a quiet place to review their baby's progress during the past week, discuss the baby's present condition and consider plans for the coming week's treatments.

4) Doctors should explain babies' problems and treatments slowly and in simple language.

5) Parent support groups where parents can talk about their feelings are important. Twice a week meetings are good but they should not be held during the day because most fathers are unable to attend at that time on weekdays.

6) Information meetings should be organized by NICU staff to furnish new parents of hospitalized infants with comprehensive information about prematurity and the care and development of VLBW premature infants. Meetings could be held fortnightly, alternating between evenings and days to accommodate the needs of shift workers. Sunday afternoon meetings are another possibility.

7) Paediatricians should have a list of names of parents who have had

VLBW premature infants and who would be willing to have new parents telephone them from time to time to learn from their experiences and to receive emotional support from them.

From Parents of a Chronically Ill Infant

1) Prior to discharge of an infant still requiring expert care, the NICU staff should assist the parents in a planned way with the transition of care in consultation with the community-based professionals whose assistance parents are going to need.

2) To save parents much worry, time and energy, all community professionals dealing with a chronically ill infant should meet regularly as a group with parents to share information and perceptions, clarify areas of miscommunication, and reach consensus on decisions regarding the infant's medical treatment.

Conclusion

If, as a society, we are willing to spend millions of dollars on sophisticated technology to save the lives of VLBW premature infants, then we should also be willing to spend substantial sums of money to provide parents with the support they need at all stages of the process of having and rearing these special babies. Evidence already indicates (Egeland & Vaughn, 1981; Hunter et al., 1978; Lynch & Roberts, 1977) that the lack of support services may contribute to the spiralling strain which in many parents has imperilled their relationships with their infants and hence the present and future welfare of these children.

REFERENCES

Affonso, D.D. & Stichler, J.F. (March, 1980). Cesarean birth: Women's reactions. American Journal of Nursing, 468-470.

Aguilera, D. & Messick, J. (1974). Crisis intervention: Theory and methodology (2nd ed.). St. Louis: The C.V. Mosby Company.

Allan, G. (1980). A note on interviewing spouses together. Journal of Marriage and the Family, 42, 205-210.

American Academy of Pediatrics (1967). Nomenclature for duration of gestation, birthweight, and intra-uterine growth. Pediatrics, 39, 935.

Aradine, C.R. Shapiro, V. & Uman, H. (1980). Robbie: Coping with trauma in the neonatal period. In S. Fraiberg (Ed.), Clinical studies in infant mental health: The first year of life (pp. 141-163). New York: Basic.

Arbeit, S.A. (1975). A study of women during their first pregnancy. Unpublished doctoral dissertation, Yale University.

Auerbach, S.M. (1983). Crisis intervention research: Methodological considerations and some recent findings. In L. Cohen, W. Claiborn & G.A. Specter (Eds.), Crisis intervention (2nd ed.) (pp. 191-211). New York: Human Sciences Press.

Balderston, P.A. (1983). Neonatal mechanical ventilation: Current practice and future trends. In K. Stahler-Miller (Ed.), Neonatal and pediatric critical care nursing (pp. 21-47). New York; Churchill-Livingstone.

Barnard, K. (1980a). Sleep organization and motor development in premature infants. In E.J. Sell (Ed.), Follow-up of the high-risk newborn - a practical approach (pp. 92-100). Springfield, IL: Charles C. Thomas.

Barnard, K. (1980b). How nursing prevents developmental delay. In E.J. Sell (Ed.), Follow-up of the high-risk newborn - a practical approach (pp. 213-230). Springfield, IL: Charles C. Thomas.

Barrett, W. (1979). The illusion of technique. Garden City, NY: Anchor.

Battaglia, F.C. & Lubchenco, L.O. (1967). A practical classification of newborn infants by weight and gestational age. Journal of Pediatrics, 71, 159-163.

Belsky, J. (1981). Early human experience: A family perspective. Developmental Psychology, 17 (1), 3-23.

Benfield, D.G., Leib, S.A. & Reuter, J. (1976). Grief response of parents after referral of the critically ill newborn to a regional center. New England Journal of Medicine, 294, 975-978.

Bidder, R.T., Crowe, E.A. & Gray, O.P. (1974). Mothers' attitudes to preterm infants. Archives of Disease in Childhood, 49, 766-770.

Birdsong, L.S. (1981). Loss and grieving in cesarean mothers. In C.F. Kehoe (Ed.), The cesarean experience - theoretical and clinical perspectives for nurses (pp. 187-209). New York: Appleton-Century Crofts.

Blake, A., Stewart, A & Turcan, D. (1975). Parents of babies of very low birthweight: Long-term follow-up. In Parent-infant interaction, Ciba Foundation symposium No. 33 (new series), Amsterdam (pp. 271-288). Amsterdam: Associated Scientific Publishers. New York: American Elsevier.

Blankenburg, W. (1980). Phenomenology and psychopathology. Journal of Phenomenological Psychology, 11, 50-78.

Bloom, B.L. (1963). Definitional aspects of the crisis concept. Journal of Consulting Psychology, 27, 498-502.

Bocian, J.E. & Kaback, M.N. (1978). Crisis counseling, Pediatric Clinics of North America, 25, 643-650.

Boyle, M., Giffin, A. & Fitzhardinge, P. (1977). The very low birthweight infant: Impact on parents during the pre-school years. Early Human Development, 1, 191-201.

Brown, Y. (1983). Learning efforts of mothers of preterm and low birth weight infants. Unpublished master's thesis, University of Saskatchewan, Saskatoon.

Budin, P. (1907). The nursling: The feeding and hygiene of premature and fullterm infants. (W.J. Mahoney, Trans.). London; Gaston.

Cadden, V. (1966). Crisis in the family. In G. Caplan, Principles of preventive psychiatry (pp. 288-296). New York: Basic.

Calhoun, L.G., Selby, J.W. & King, H.E. (1976). Dealing with crisis. Englewood Cliffs, New Jersey: Prentice-Hall.

Caplan, G. (1966). *Principles of preventive psychiatry*. New York: Basic.

Caplan, G., Mason, E.A. & Kaplan, D.M. (1965). Four studies of crisis in parents of prematures. *Community Mental Health Journal*, *1*, 149-161.

Choi, M.W.A. (1973). A comparison of maternal psychological reactions to premature and full-size newborns. *Maternal-child Nursing Journal*, *2*(1), 1-13.

Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine*, *38*, 300-314.

Cohen, S.E. & Beckwith, L. (1979). Preterm infant interaction with the caregiver in the first year of life and competence at age two. *Child Development*, *50*, 767-776.

Cohen, L., Claiborn, W. & Specter, G.A. (Eds.) (1983). *Crisis intervention* (2nd ed.). New York: Human Sciences Press.

Cohen, L.H. & Nelson, D.W. (1983). Crisis intervention: An overview of theory and technique. In L. Cohen, W. Claiborn & G.A. Specter (Eds.), *Crisis intervention* (2nd ed.) (pp. 13-26). New York: Human Sciences Press.

Colaizzi, P.F. (1978). Psychological research as the phenomenologist views it. In R.S. Valle & M. King (Eds.), *Existential-phenomenological alternatives for psychology* (pp. 48-71). New York: Oxford University Press.

Cramer, B. (1982). Interview with parents of premature infants. In M.H. Klaus & J.H. Kennell, Parent-infant bonding (2nd ed.) (pp.181-185). St. Louis: the C.V. Mosby Company.

Crnic, K.A., Greenberg, M.T., Ragozin, A.S., Robinson, N.M. & Basham, R.B. (1983). Effects of stress and social support on mothers and premature and full-term infants. Child Development, 54, 209-217.

Crnic, K.A., Ragozin, A.S., Greenberg, M.T., Robinson, N.M. & Basham, R.B. (1983). Competence of preterm and full-term infants during the first year of life. Child Development, 54, 1199-1210.

Cummings, S.T. (1976). The impact of the child's deficiency on the father: A study of fathers of mentally retarded and of chronically ill children. American Journal of Orthopsychiatry, 46, 246-255.

David, D.S. & Brannon, R. (Eds.) (1976). The forty-nine percent majority. Reading, MASS: Addison-Wesley.

Deegan, P.E. (1981). An empirical phenomenological study of failing to learn. Journal of Phenomenological Psychology, 12 (231-259).

Denzin, N.K. (1970). The research act. Chicago: Aldine.

Drillien, C.M. (1964). The growth and development of the prematurely born infant. Baltimore: Williams and Wilkins.

Drillien, C.M., Thomson, A.J.M. & Burgoyne, K. (1980). Low-birthweight children at early school-age: A longitudinal study. Developmental Medicine and Child Neurology, 22(1), 26-47.

Dubois, D.R. (1975). Indications of an unhealthy relationship between parents and premature infants. Journal of Obstetrics, Gynecology and Neonatal Nursing, 4, 21-24.

Duhamel, T., Lin, S., Skelton, A. & Hantke, L. (1974). Early parental perceptions and the high risk neonate. Clinical Pediatrics, 13, 1052-1056.

Egeland, B. & Vaughn, B. (1981). Failure of "Bond Formation" as a cause of abuse, neglect, and maltreatment. American Journal of Orthopsychiatry, 51, 78-84.

Elliott, M.R. (1983). Maternal infant bonding: Taking stock. The Canadian Nurse, 79 (8), 23-31.

Ellwood, D.A. & Anderson, A.B.M. (Eds.) (1981). The cervix in pregnancy and labour. Edinburgh: Churchill-Livingstone.

Enriquez, M., Harrell, H. & Putman, M. (1980). Role of parent groups for an intensive care nursery. In E.J. Sell (Ed.), Follow-up of the high risk newborn - a practical approach (pp. 255-264). Springfield, IL: Charles C. Thomas.

Erikson, E.H. (1959). Identity and the life cycle. Psychological Issues Monograph, 1(1). New York: International Universities.

Evans, M. (1985). Paternal attitudes relevant to becoming a father of a hospitalized premature infant. Unpublished master's thesis. University of Alberta, Edmonton.

Field, T. (1977). Effects of early separation, interactive deficits and experimental manipulations on infant-mother face-to-face interaction. Child Development, 48, 763-771.

Fleischman, A.R. (1986). The immediate impact of the birth of a low birth weight infant on the family. Zero to Three, VI (4), 1-5.

Fraiberg, S.H. (1980). Clinical studies in infant mental health: The first year of life. New York: Basic

Freidson, E. (1960). Client control and medical practice. American Journal of Sociology, 56, 374-382.

Geiger, J. (1986, February 19). Canadians dying out, study says. Edmonton Journal, p. B1.

Giorgi, A. (1970). Psychology as a human science. New York: Harper & Row.

Goldberg, H. (1980). The new male. New York: The New American Library.

Goldberg, S., Brachfeld, S. & DiVitto, B. (1980). Feeding, fussing and play: Parent-infant interaction in the first year as a function of prematurity and perinatal medical problems. In T.M. Field, S. Goldberg, D. Stern & A.M. Sostek (Eds.), High-risk infants and children-adult and peer interactions (pp. 133-153). New York: Academic.

Goldberg, S. & DiVitto, B.A. (1983). Born too soon. San Francisco: W.H. Freeman.

Guba, E. (1979). Naturalistic inquiry. Improving Human Performance Quarterly, 8, 268-276.

Hack, M., DeMonterice, D., Merkatz, I.R., Jones, P. & Fanaroff, A.A. (1981). Rehospitalization of the very-low birth-weight infant. American Journal of Diseases of Children, 135, 263-266.

Halpern, H.A. (1973). Crisis theory: a definitional study. Community Mental Health Journal, 9, 342-349.

Harper, R.G., Sia, C., Sokal, S. & Sokal, M. (1976). Observations on unrestricted parental contact with infants in the neonatal intensive care unit. The Journal of Pediatrics, 89, 441-445.

Herzog, J.M. (1979). Disturbances in parenting high-risk infants: Clinical impressions and hypotheses. In T.M. Field, A.M. Sostek, S. Goldberg & H.H. Shuman (Eds.), Infants born at risk (pp. 357-363). Jamaica, NY: Spectrum.

Hobel, C.J. (December, 1980). The role of a regional perinatal program for the prevention of prematurity. In T. Paton (Ed.), Proceedings of the Second Symposium on the Prevention of Handicapping Conditions of Prenatal or Perinatal Origin (pp. 105-111). Calgary, Alberta: Alberta Social Services and Community Health.

Hollingshead, A.B. & Redlich, F.C. (1958). Social class and mental illness. New York: John Wiley.

Hunter, R.S., Kilstrom, N., Kraybill, E.N. & Loda, F. (1978). Antecedents of child abuse and neglect in premature infants: A prospective study in a newborn intensive care unit. Pediatrics, 61, 629-635.

Huston, T.L. & Robins, E. (1982). Conceptual and methodological issues in studying close relationships. Journal of Marriage and the Family, 44, 901-925.

Hymovich, D.P. & Chamberlin, R.W. (1980). Child and family development. New York: McGraw-Hill.

Jaffe, D.T. (1985). Self-renewal. Journal of Humanistic Psychology, 25 (4), 99-124.

Jeffcoate, J.A., Humphrey, M.E. & Lloyd, J.K. (1979). Role perception and response to stress in fathers and mothers following pre-term delivery. Social Science and Medicine, 13A, 139-145.

Kaplan, D.M. & Mason, E.A. (1960). Maternal reactions to premature birth viewed as an acute emotional disorder. American Journal of Orthopsychiatry, 30, 539-547.

Keen, E. (1978). Psychopathology. In R.S. Valle & M. King (Eds.), Existential-phenomenological alternatives for psychology (pp. 234-264). New York: Oxford University Press.

Keller, C.A. (1981). Epidemiological characteristics of preterm births. In S.A. Friedman & M. Sigman (Eds.), Preterm birth and psychological development (pp. 3-15). New York: Academic.

Kennell, J.H. & Klaus, M.H. (1982). Caring for the parents of premature or sick infants. In M.H. Klaus & J.H. Kennell, Parent-infant bonding (2nd ed.) (pp. 151-226). St. Louis: The C.V. Mosby Company.

Kerlinger, F.N. (1973). Foundations of behavioral research (2nd ed.). New York: Holt, Rinehart and Winston.

Klaus, M.H. & Kennell, J.H. (1976). Maternal-infant bonding. St. Louis: The C.V. Mosby Company.

Kliman, G.W. & Rosenfeld, A. (1980). Responsible parenthood. New York: Holt, Rinehart and Winston.

Kockelmans, J.J. (1967). Edmund Husserl's phenomenological psychology. Pittsburgh: Duquesne University Press.

Korner, A.F. (1981). Sensory responsiveness and social behavior in the neonatal period: a review of chapters 9 and 10. In S.L. Friedman & M. Sigman (Eds.), Preterm birth and psychological development (pp. 207-215). New York: Academic.

Korner, I.N. (1973). Crisis reduction and the psychological consultant. In G.A. Specter & W.L. Claiborn (Eds.), Crisis intervention (pp. 30-45). New York: Behavioral Publications.

Leifer, M. (1977). Psychological changes accompanying pregnancy and motherhood. Genetic Psychology Monographs, 95, 55-96.

Levine, S. (1966). Sex-role identification and parental perceptions of social competence. American Journal of Mental Deficiency, 70, 822-824.

Levy, S.M. (1981). The experience of undergoing a heart attack: The construction of a new reality. Journal of Phenomenological Psychology, 12, 153-171.

Lewis, M.S., Gottesman, D. & Gutstein, S. (1979). The course and duration of crisis. Journal of Consulting and Clinical Psychology, 47, 128-134.

Lindemann, E. (1944-1945). Symptamology and management of acute grief. American Journal of Psychiatry, 101, 141-148.

Lissenden, J.V. (1984). Parental attitudes to premature very low birthweight babies. In P.A. Field (Ed.), Perinatal nursing (pp. 122-145). Edinburgh: Churchill-Livingstone.

Lissenden, J. & Ryan, M. (1982). Parents' view of newborn intensive care. The Australian Nurses' Journal, II(6), 34-36.

Luterman, D. (1979). Counseling parents of hearing-impaired children. Boston: Little, Brown.

Lynch, M.A., & Roberts, J. (1977). Predicting child abuse: Signs of bonding failure in the maternity hospital. British Medical Journal, 1, 624-626.

Mangurten, H.H., Slade, C. & Fitzsimons, D. (1979). Parent-parent support in the care of high-risk newborns. Journal of Gynecological Nursing, September/October, 275-277.

Marton, P., Minde, K. & Ogilvie, J. (1981). Mother-infant interactions in the premature nursery: A sequential analysis. In S.L. Friedman & M. Sigman (Eds.), Preterm birth and psychological development (pp. 179-205). New York: Academic.

Marton, P., Minde, K. & Perrotta, M. (1981). The role of the father for the infant at risk. American Journal of Orthopsychiatry, 51, 672-679.

McCarton, C.M. (1986). The long-term impact of a low birth weight infant on the family. Zero to Three, VI, 6-10.

McConville, M. (1978). The phenomenological approach to perception. In R.S. Valle & M. King (Eds.), Existential-phenomenological alternatives for psychology (pp. 94-118). New York: Oxford University Press.

Mehan, H. & Wood, H. (1975). The reality of ethnomethodology. New York: John Wiley.

Merleau-Ponty, M. (1962). Phenomenology of perception. London: Routledge & Kegan Paul.

Merton, R.K. & Kendall, P.L. (1946). The focussed interview. American Journal of Sociology, 51, 541-557.

Miller, B.F. & Keane, C.B. (1978). Encyclopedia and dictionary of medicine, nursing and allied health (2nd ed.). Philadelphia: W.B. Saunders.

Minde, K., Ford, L., Celhoffer, L. & Boukydis, M. (1975). Interactions of mothers and nurses with premature infants. Canadian Medical Association Journal, 113, 741-745.

Minde, K., Shosenberg, N., Marton, P., Thompson, J., Ripley, J. & Burns, S. (1980). Self-help groups in a premature nursery - a controlled evaluation. The Journal of Pediatrics, 96, 933-940.

Minde, K., Trehub, S., Corter, C., Boukydis, C., Celhoffer, L. & Marton, P. (1978). Mother-child relationships in the premature nursery: An observational study. Pediatrics, 61, 373-379.

Mitchell, R.E. & Trickett, E.J. (1980). Task force report: Social networks as mediators of social support. Community Mental Health Journal, 16, 27-44.

Moss, D. (1978). Brain, body and world: Perspectives on body-image. In R.S. Valle & M. King (Eds.), Existential-phenomenological alternatives for psychology (pp. 73-93). New York: Oxford University Press.

Newman, L.F. (1980). Parents' perceptions of their low birth weight infants. Paediatrician, 9, 182-190.

Oakley, A. (1979). Becoming a mother. London: Martin Robertson.

Owens, C. (1960). Parents' response to premature birth. American Journal of Nursing, 60, 1113-1118.

Parke, R.D. (1981). Fathering. New York: Fontana.

Perlman, N.B. (1986). What are they doing to my baby now? Zero to Three, VI (4), 10-11.

Philipp, C. (1984). The relationship between social support and parental adjustment to low birthweight infants. Social Work, 29, 547-550.

Polakow, V. (1984). Reflections on pedagogy, research and praxis. Phenomenology + Pedagogy, 2(1), 29-35.

Powell, D.R. (1979). Family-environment relations and early childrearing: The role of social networks and neighborhoods. Journal of Research and Development in Education, 13(1), 1-11.

Prescott, M.P. & Valle, R.S. (1978). An existential-phenomenological look at cognitive-developmental theory and research. In R.S. Valle & M. King (Eds.), Existential-phenomenological alternatives for psychology (pp. 153-165). New York: Oxford University Press.

Prugh, D. (1953). Emotional problems of the premature infant's parents. Nursing Outlook, 1, 461-464.

Reinharz, S. (1983). Phenomenology as a dynamic process. Phenomenology + Pedagogy, 1(1), 77-79.

Roberts, F.B. (1977). Perinatal Nursing. New York: McGraw-Hill.

Romanyshyn, R.D. (1978). Psychology and the attitude of science. In R.S. Valle & M. King (Eds.), Existential-phenomenological alternatives for psychology (pp. 18-47).

Sameroff, A.J. (1981). Longitudinal studies of preterm infants: A review of chapters 17-20. In S.L. Friedman & M. Sigman (Eds.), Preterm birth and psychological development. New York: Academic.

Schraeder, B.D. & Donar, M.E. (1983). The child with chronic respiratory failure: A special challenge. In K. Stahler-Miller (Ed.), Neonatal and pediatric critical care nursing (pp. 119-147). New York: Churchill-Livingstone.

Selby, J.W., Calhoun, L.G. Vogel, A.V. & King, H.E. (1980). Psychology and human reproduction. New York: The Free Press.

Shainness, N. (1963). The psychologic experience of labour. New York State Journal of Medicine, 63, 2923-2932.

Shneidman, E. (1973). Crisis intervention: some thoughts and perspectives. In G.A. Specter & W.L. Claiborn (Eds.), Crisis intervention (pp. 9-15). New York: Behavioral Publications.

Shosenberg, N. (1980a). The premature infant. A handbook for parents. Toronto: The Hospital for Sick Children.

Shosenberg, N. (1980b). Self-help groups for parents of premature infants The Canadian Nurse, 76 (7), 30-34.

Shosenberg, N. & Lennox, K. (1985). Dear parents of premature babies: Family experiences with premature birth. Ottawa: The Canadian Institute of Child Health.

Silcock, A. (1984). Crises in parents of prematures: An Australian study. British Journal of Developmental Psychology, 2, 257-268.

Silvers, R.J. (1982). Discourse in a search for a communicative relationship. In V. Darroch & R.J. Silvers (Eds.) Interpretive human studies (pp. 173-214). Washington, DC: University Press of America.

Sluckin, M.H. & Sluckin, A. (1982). Mother-to-infant "bonding". Journal of Child Psychology and Psychiatry and Allied Disciplines, 23, 205-221.

Smith, J.E. (1983). Preparation for fatherhood. Unpublished master's thesis. University of Alberta, Edmonton.

Spignesi, A. (1981). The scientific investigation of emotion judgments: The possibility re-examined. Journal of Phenomenological Psychology, 12, ~~107-130.~~

Statistics Canada (1984). Vital statistics - births and deaths, 1982, Vol. 1. Ottawa: Minister of Supply and Services Canada.

Stedman, T.L. (1982). Stedman's Medical Dictionary (24th ed.). Baltimore: Williams & Wilkins.

Stewart, A.L., Reynolds, E.O.R. & Lipscomb, A.P. (1981). Outcome for infants of very low birthweight: Survey of world literature. Lancet, 1, 1038-1040.

Taplin, J.R. (1971). Crisis theory: Critique and reformulation. Community Mental Health Journal, 7, 13-23.

Trause, M.A. & Irvin, N.A. (1982). Care of the sibling. In M.H. Klaus & J.H. Kennell (Eds.), Parent-infant bonding (2nd ed.). St. Louis: The C.V. Mosby Company.

Unger, D.G. & Powell, D.R. (1980). Supporting families under stress: The role of social networks. Family Relations, 29, 566-574.

Valle, R.S. & King, M. (1978). An introduction to existential-phenomenological thought in psychology. In R.S. Valle & M. King (Eds.), Existential-phenomenological alternatives for psychology (pp. 6-17). New York: Oxford University Press.

Van den Berg, J.H. (1972). A different existence. Pittsburgh: Duquesne University Press.

Van Kaam, A. (1966). Existential foundations of psychology. Pittsburgh: Duquesne University Press.

Van Manen, M. (1984). Practicing phenomenological writing. Phenomenology + Pedagogy, 2(1), 36-69.

Vaucher, Y. (1980). Growth in the highrisk newborn. In E.J. Sell (Ed.), Follow-up of the high risk newborn - a practical approach (pp. 101-117).

Verny, T. (1981). The secret life of the unborn child. New York: Summit.

Walker, K.N., MacBride, A. & Vachon, M.L.S. (1977). Social support networks and the crisis of bereavement. Social Science & Medicine, 11, 35-41.

Wandersman, L., Wandersman, A. & Kahn, S. (1980). Social support in the transition to parenthood. Journal of Community Psychology, 8, 332-342.

Werner, W. (1983). Exploring the experiences of mentally retarded older adults in group home settings. Review of unpublished Ph.D. dissertation by E.M. Thurman, University of Michigan, 1983. Phenomenology + Pedagogy, 1(2), 217-220.

Werthmann, M. W. Jr. (1981). Medical constraints to optimal psychological development of the preterm infant. In S.L. Friedman & M. Sigman (Eds.), Preterm birth and psychological development (pp. 17-39). New York: Academic.

Whaley, P.A., Gosling, C.G. & Schreiner, R.L. (1979). Relieving parental anxiety. A booklet for parents of an infant in NICU. Journal of Obstetrics, Gynecologic and Neonatal Nursing, 8, 49-55.

Willems, E.P. & Rauch, L. (Eds.) (1969). Naturalistic viewpoints in psychological research. New York: Holt, Rinehart and Winston.

Wright, B.M. & Zucker, R.A. (1980). Parental responses to competence and trauma in infants with reproductive casualty. Journal of Abnormal Child Psychology, 8, 385-395.

Yu, V.Y.H., Jamieson, J. & Astbury, J. (1981). Parents' reactions to unrestricted parental contact with infants in the intensive care nursery. The Medical Journal of Australia, 1, 294-296.

Zeskind, P.S. & Iacino, R. (1984). Effects of maternal visitation to preterm infants in the neonatal intensive care unit. Child Development, 55, 1887-1893.

APPENDIX 1

Parents' Experience of Having a Very Low Birthweight Premature Baby

Back-up Questionnaire for Conducting Semi-structured Interviews with Parents

M = Mother
F = Father

If a question is directed to both spouses, no initial letter precedes it.

Prenatal Period

1) How long have you been married?

2) Do you have any other children besides ...?

3) (If yes): What are their names and how old are they?

4) M: Did you have any pregnancy and delivery problems with any of these children?

5) Was your pregnancy with ... a planned pregnancy?

6) When was ... born and do you remember her/his birthweight?

7) M: Can you recall what your health was like before and during your pregnancy with ...?

8) Do you remember ever building a picture of the kind of baby you wanted to have?

9) M: While you were pregnant with ..., did you ever think of him/her as a separate individual?

10) M: How much warning did you have that ... was going to be born prematurely?

11) M: What warning signals were there?

12) Can you remember how prepared you were to have a premature baby, for instance mentally, emotionally and with practical arrangements?

13) How much knowledge did you each have beforehand about babies in general and premature babies in particular?

14) To what extent were you able to prepare (sibling/s) for changes in daily routines while mom and the new baby were in hospital?

Delivery and the Immediate Postpartal Period

15) M: Was ... born naturally or did you have a caesarean?

16) Were you able to be together for ...'s birth?

17) (If no):
F: What was it like waiting in the hospital for ... to be born?

18) M: How long were you in the hospital?

19) M: Did you have any complications?

20) F: Can you describe how your life was affected while (wife) was in hospital?

21) Do you each have families living nearby?

22) Do you each have brothers and sisters?

23) Can you recall how your families and friends reacted to ...'s birth?

24) How did (sibling/s) react?

25) Can you talk about the medical problems ... had?

26) How long did her/his condition continue to worry you both?

27) Did ... have any serious setbacks or did he/she progress normally?

28) When did each of you first see ...?

29) Can you each remember what you thought and felt when you first saw ...?

30) Can you each recall how you felt when you visited neonatal intensive care unit for the first time?

31) What kinds of contact did you each have with ... while she/he was in hospital?

32) Can you each remember when ... first looked at you?

33) Can you remember when ... first smiled at you?

34) When was the first time you were allowed to touch ...?

35) What was that like for you?

36) When did each of you first feel ... was really yours?

37) What were your thoughts and feelings about having given birth to a tiny, premature baby?

38) Some parents have believed it was their faults their babies were born prematurely. Did either of you ever think this?

39) Some parents have also felt that they have somehow failed by not having had a healthy fullterm baby. Did this ever come to mind for either of you?

40) While ... was in hospital, how much time did the two of you have to be alone together?

41) How much time were you each able to spend every day with (sibling/s)?

42) How much time were you each able to spend with family and friends?

43) How did (sibling/s) react to changes in daily routines because you had to spend so much time at the hospital?

44) What arrangements were you able to make to keep your home running normally while (mother) was in hospital and then while ... was in hospital?

45) How easy or how hard did you find it to start feeling close to ... while he/she was still in hospital?

46) (Where applicable):
M: Compared to your previous deliveries, what made this one easier or harder?

47) M: What was your health like when you were discharged from hospital?

48) M: What was it like to come home without ...?

49) M: Did the hospital staff explain why they thought it was important for you to supply breast milk for ...?

50) M: Were you able to supply enough breast milk?

51) M: What kind of experience was it for you?

52) What thoughts do you both have about the attention ... and you as parents received from the nurses, the doctors and the other staff?

53) Did the hospital provide any kind of support to help you cope with all the ups and downs you experienced while ... was in hospital?

54) How long was ... in the critical care nursery and how long in the convalescent nursery?

55) Can you recall the date ... was discharged from the hospital?

After the Baby Comes Home

56) When ... first came home, was her/his state of health still a source of worry to you both?

57) Did ... ever have to return to hospital for any reason?

58) (If yes):

59) What was this experience like for you?

60) How did (sibling/s) and your families react?

61) What is ...'s state of health now?

62) How did ...'s (sibling/s) act toward him/her when he/she first came home?

63) How are they getting on now?

64) Have you had any problems with ... since she/he has come home?

65) To what extent have home visits from the public health nurse been helpful to you?

66) What other kinds of assistance have you found most helpful?

67) Now that ... has been home a while, have the attitudes of your family and friends about your having a premature baby changed at all?

68) Looking back, can you remember the main thoughts and feelings you had during the whole experience?

69 F: Do you recall developing any health problems or that health problems you had became worse as a result of the pressure you were under?

70) F: Was your work life affected in any way by ...'s birth?

71) F: Did you take time off from work?

72) F: Did you find yourself doing parenting tasks and household chores you hadn't done before?

73) (If yes):
What kind of experience was this for you?

74) F: Are you still doing any of the new activities?

75) How are chores and caring for (... or "the children") now organized?

76) Did you have extra expenses because of ...'s premature birth and long stay in hospital?

77) Some families' finances have become shaky because of unemployment. Has this been a problem for you?

78) Do you think you have suffered from the whole experience of having ... physically or emotionally or in any other ways?

79) M: Have you had any health problems since having ...?

80) (If yes):

M: Have these problems affected your ability to care for ... and any other aspects of your life?

81) Has having ... been a positive experience for you in any way?

82) Have any of your relationships with others suffered or been strengthened as a result of the experience?

83) Have your relationships with (sibling/s) changed at all?

84) How do you now feel about having had a very premature baby?

85) Is it affecting your lives in any way right now?

86) What has helped you most during the whole experience?

87) What aspects have been the hardest to deal with?

88) Do you have a particular philosophy that has helped you through all the bad times?

89) Has the total experience affected the relationship between you in any way?

90) Have you had any other stressful situations to deal with besides those connected with ...'s birth?

91) Did these situations affect how you coped with the problems that arose around having ...?

92) To what extent have you found your families to be a source of support?

93) It often happens that our experiences with our own parents influence how we act when we have our own children. So I'm interested to know how things were for you when you were growing up.

94) To what extent have you had support from your friends?

95) Right now, are you in any kind of support group for parents of premature babies?

96) Have you been involved in any self-help activities like reading about premature babies, phoning professionals for advice or talking to other parents who've had experiences like yours?

97) What kind of help do you wish you had had and what help would you like right now?

98) Has .. been for a check-up at Glenrose Hospital recently?

99) (If yes):

What did they say about his/her development?

100) How does your paediatrician see ... progressing?

101) Do you agree with what these professionals are saying?

102) What do you anticipate the next 5 years will be like?

103) What about the next 10-20 years?

104) Do you worry now about ...'s health?

105) Do you worry generally about ...'s future?

106) Do you feel differently towards ... than you do towards (sibling/s)?

107) Do you think the time you were separated from ... while she/he was in hospital has affected how you feel towards her/him now?

108) Has your experience of having ... affected your thinking about having anymore children?

109) What do you think of the treatment ... and each of you received from the nurses, the doctors and other professionals?

110) What did you like and what did you not like?

111) Do you have any ideas for improvements?

112) Do you have any recommendations that would help parents who have babies like yours in the future?

113) What has this experience of being interviewed been like for you?

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Department of Educational Psychology
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Canada T6G 2G5

6-102 Education North, Telephone (403) 432-5245

APPENDIX 2

Re: M.Ed. Thesis: Having a Very Low Birthweight Premature Baby - The Experience of Parents

I am writing to ask if you can assist me in finding parents to interview for the above study.

The parents I am looking for would -

- be living in a stable relationship, whether married or not;
- live within the city of Edmonton;
- have had a very low birthweight baby of less than 1501 grams (3.3 lbs or thereabouts);
- as far as you know, intend to keep their baby;
- have a baby that appears likely to survive infancy;
- have had the baby home for at least a month.

I wish to begin interviewing as soon as possible, ending in January, 1985.

In case you are able to assist me, I am enclosing 3 copies of a letter for you to mail to interested parents with stamped addressed return envelopes and I can let you have more if necessary. Also enclosed are 3 stamped envelopes for sending the material to parents. The letter to parents, together with the enclosed copy of the rationale and nature of the study, will give you pertinent background information.

I shall call you in a week's time to ascertain whether you are in a position to assist me and shall, of course, understand if you are not able to do so. In that case, I would appreciate if you would please return the mailing material to me in the enclosed brown stamped, self-addressed envelope. Many thanks.

Sincerely,

Brenda Manasse

Encs.

University of Alberta
Edmonton
Canada T6G 2G5

Department of Educational Psychology
Faculty of Education
6-102 Education North, Telephone (403) 432-5245

APPENDIX 3

Re: M.Ed. Thesis: Having a Very Low Birthweight Premature Baby - The Experience of Parents

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TO PARENTS WHO MAY BE INTERESTED IN PARTICIPATING IN THE ABOVE STUDY

Dear Parents:

Let me introduce myself. I am a student in the last year of my master's degree program in the Department of Educational Psychology, University of Alberta. I am trained and experienced in counselling children, adults and couples. Although I have never had children of my own, I have done volunteer work with parents and their children for the past 20 years and so have had first-hand experience of the many challenges parents face. My main concern is to support parents in their demanding job, particularly while their children are still babies, so they can lay the best possible foundations for strong, loving relationships between themselves and their children.

The aims of my study are firstly, to add to the existing knowledge about the impact of a very low birthweight infant on parents' lives and secondly, to discover if these parents are encountering problems that have not yet come to the notice of hospitals and other community sources of help. Unlike other research in this area, my study will concentrate on parents' information given at their own pace and on topics of their choice.

I will meet with couples and invite them to talk as long as they wish about their thoughts and feelings on having a very low birthweight premature baby. We will meet a minimum of twice with three meetings being more likely. I am open to meeting either in your home or at the university and I would be available days, evenings and weekends. For legal reasons, I will ask parents to each sign a form giving me permission to audiotape the sessions. I expect each session to take 1-2 hours. Your information will be treated in strictest confidence and your names will not be used in the thesis. Parents will be free to withdraw from the study at any time. When I have completed the study, I shall send participating parents a summary of my findings.

Your original contact person will have told you the criteria I'm looking for in parents, but here they are again:

- they are living in a stable, continuing relationship, whether married or not;
- live within the city of Edmonton;
- their baby's birthweight was less than 1501 grams (3.3 lbs);
- the baby has been home for at least a month.

If you'd like more information, please call me weekdays early mornings (before 8 a.m.) and evenings, and weekends. My home number is 429-3567. I wish to commence meeting with parents as soon as possible, so I'd appreciate your mailing the tearoff sheet below as soon as you've decided whether or not you're interested in participating. A stamped, addressed envelope is enclosed for your use. If you are interested, I'll call you to arrange our first meeting. Meanwhile, I hope all is going well with you and your baby.

Sincerely,

Brenda Manasse

Enc.

- -

Parents' Names ....

Address ....

Phone: Home .... Work .... Work ....

Please check one of the responses below

Yes, we would like to participate in the study ......

No, we do not wish to participate in the study ......

APPENDIX 4

Demographic Data - Mothers

	Barb	Beth	Janet	Pam	Sharon
Age	26	33	32	32	23
Years Married	5	11	4	7	5
Occupation	Homemaker/ Parttime Bookkeeper	Fulltime Homemaker	Secretary Parttime Homemaker	Fulltime Homemaker	Fulltime Homemaker
Education					
High School	12	12	12	11	12
University	--	Courses in Special Ed.	--	--	--
Other Post-secondary Study and Training	--	Family Life Educator	2 years	--	--

Demographic Data - Fathers

	Noel	Philip	Will	Kevin	Jim
Age	32	32	31	32	26
Years Married	5	11	4	7	5
Occupation	Sheet Metal Mechanic	Manager	Plumber and Steamfitter	Compositor	Automotive Partsperson
Education					
High School	10	12	Matriculation	11	12
University	--	--	2 years	--	--
Other Postsecondary Study and Training	4 years	Business Courses	4 years	--	3 years

APPENDIX 5

INFORMED CONSENT FORM

PROJECT TITLE: Having a very low birthweight premature baby - the experience of parents.

INVESTIGATOR: Brenda Manasse Telephone: Home: 429-3567
Dept: 432-5245

The purpose of this research project is to increase information and understanding of the special experiences of parents who have had a very low birthweight baby.

Interviews will be conducted at least 2 times and each interview will last approximately one hour. Parents will be invited to discuss whatever aspects of their experience emerge as most important for them. The investigator will supplement these personal accounts with questions so that a complete account will emerge of events around the mother's pregnancy, around delivery and the post-natal period, and around the daily lives of parents and other family members following the baby's arrival home.

Interviews will be tape-recorded and these tapes will only be heard by the investigator and her thesis committee. The taped information will be incorporated in the final report (the thesis) which will be available in the Herbert Coutts Library, Education Centre, University of Alberta.

There may be no direct benefits to the participants in this study.

This is to certify that I ....
(print name)
hereby agree to participate as a volunteer in the above named project.

I hereby give permission to be interviewed and for these interviews to be tape-recorded. I understand that, at the completion of the research, the tapes will be erased. I understand that the information may be published but my name will not be associated with the research.

I understand that I am free to deny any answer to specific questions. I also understand that I am free to withdraw my consent and terminate my participation at any time without penalty.

Signature: ....

APPENDIX 6

INFORMATION SHEET

NAME: Wife: Husband:

ADDRESS:

PHONE: Home: Business: W: H:

AGE: Wife: Husband:

NO. OF YEARS MARRIED OR COHABITING:

AGES WHEN PREMATURE BABY BORN: Wife: Husband:

NAMES AND AGES AND SEX OF OTHER CHILDREN, IF ANY:

EDUCATION:

	Wife	Husband
High School – Highest grade completed		
University – Degrees or years of study		
Other Post-Secondary Study and Training –		

OCCUPATION: Wife: Husband: